A Narrative Analysis of Dementia Caregivers' Experiences, Before and After the Decision to Transition the Care Recipient into Residential Aged Care

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Arts

in

Psychology

at Massey University, Manawatu, New Zealand

Faye Wright

2020

Abstract

For dementia caregivers, making the decision to transition the care recipient into residential aged care (RAC) is a significant decision. Dementia activates progressive changes in both physical and cognitive functioning, which affects behaviour, personality, and mood for the person living with dementia. Because of these physcial and mental changes, a majority of caregivers will experience many challenges and situations that will influence their decision for RAC for the care recipient. Using interviews on sleep and wellbeing across the trajectory of dementia care, this study specifically examined caregivers' experiences before and after transitioning the care recipient to RAC. Interviews with eighteen caregivers of people with dementia who had since moved into RAC were analysed. Eight of the care recipients died after admission to RAC and before the interview was conducted. Narrative analysis was used to explore caregivers' accounts. Key narratives identified were: 'This is why I had to' and 'They said I need to'. These narratives demonstrate that the decision-making process commonly begins with an accumulation of factors, but the decision is only made when the factors become unmanageable for the caregivers. The entire process is underpinned by the negative shared social understandings of RAC, which underlies the reluctance from caregivers to make this transition. The narrative 'It was a last resort', therefore, highlights resistance to the transition even when the caregivers' own wellbeing is affected. After the decision, however, caregivers describe relief regarding the decision, which was captured in the narrative 'I made the right decision'. After the care recipient passes away, caregivers used the narrative 'This is how I am adjusting' to encapsulate the re-structuring processes caregivers experience. Through this re-structuring process caregivers narrate establishing new identities, finding purpose, and experiencing agency.

Acknowledgements

First of all I wish to thank the participants whose stories provided the foundation for this project. Without their willingness to share, their courage, and sincerity, this project would not have been possible. Not only will their efforts provide me with knowledge and understanding but they will also lend critical visibility to the experiences of transitioning the care recipient into an RAC facility and afterwards, to anyone who is connected to dementia.

To my husband and family. Without your encouragement, love, and tolerance I would not have been able to complete this work. I thank you for not giving up on me. Wayne you are my rock and I love you. Britany, you were my inspiration to begin this journey and thankfully you taught me how to reference! I love you. Brandon, thank you for being there when I needed to talk and thank you for knowing when I needed a meal cooked. I love you.

Mum and Dad. You are no longer here but it was your encouragement, love, and support that started my belief that I could do and be anything. You fostered my academic side and for that I will always be grateful. Love you both for all eternity.

To my two patient, understanding, and supportive supervisors; Mary Breheny and Rosemary Gibson. Your wealth of knowledge was astounding, your support never ending, and your guidance invaluable. You have given me confidence to believe in myself and my work while inspiring me to ever greater in-depth critical thinking. For this I thank you both with all my heart.

Table of Contents

Glossary

Term	Definition
Adult Children Caregivers	Children and grandchildren of care recipients who are caregivers.
Caregiving	A term used in this thesis to describe unpaid caregiving.
Care Recipient	Person who is being cared for by the caregiver.
Dementia	Umbrella term for a chronic condition that activates physical changes in the brain leading to a loss of brain function.
Family Caregivers	Family members of care recipients who are caregivers.
Formal caregiver	A term for a caregiver who is paid by a professional or community health care provider.
Informal caregiver	A term for a caregiver who is generally unpaid and not a formal caregiver.
Residential Aged Care	A term for care in a residential aged care facility.
RAC Facility	A facility where residential age care is provided on a permanent basis.
Respite or Respite Care	A term for care in a residential aged care facility but only for a limited period of time.
Transition or Transitioning	A term that refers to moving a care recipient into a RAC facility.

Chapter 1: Introduction

Myself as Researcher

I am a daughter, who lovingly cared for my mother during her final years, alongside my sister and brother-in-law. My experiences as a caregiver of a person living with dementia was complex, challenging, and rewarding. It was complex because I was not alone in this journey but alongside many other people such as health professionals and family. Communication, therefore, during this time frequently became stressful. However, I also recognised that language was the vital link to moving forward with my mother's care. It was challenging because of the complexity of the symptoms that came with dementia. This made it difficult to meet the needs of my mother, siblings, and health professionals as well as my own needs. It was rewarding because those last years with my mother healed many 'wounds' that had been previously created through my mother's actions and my own perceptions of those actions. Most importantly, this experience not only fuelled my interest in dementia but founded my academic interest in becoming a counsellor.

It was during my years of training to be a counsellor that I first came into contact with narrative therapy, whereupon absolute knowledge claims were examined in connection to social processes and interchanges. At this time, I reflected back to my own experience with my mother and started to question how had the social context of residential aged care (RAC) affected my own and my sister's decision-making processes. I wondered that if society and our family held a different view of RAC facilities would we have resisted using them for so long? How would this have changed my experience? I may never fully be able to answer this question in retrospect but what I do know is that there would have been a different approach taken. I also believe that if those involved had the knowledge prior to transitioning my mother that was acquired after the transition, resistance would have been less.

During my counselling training, I had the privilege of counselling caregivers of people living with dementia. This experience helped me acquire insight into the uniqueness of each individual situation. I witnessed that even when symptoms were similar, timelines for and impacts of those symptoms were profoundly different, making each caregivers' experience distinct from that of other caregivers. The uniqueness was also dependent on the support that was available to that person. Similar to my own experience, social exchanges and interchanges had significant influence on outcomes. Likewise, during counselling I was in a position where I regularly heard the negativity that surrounded RAC facilities. Because of these beliefs I also witnessed the struggle that caregivers experienced when deciding whether or not to choose RAC for the care recipient.

The above experiences have heightened my understanding of how social contexts interact with decision-making processes. Furthermore, I have an enriched sense of the impact of social processes and interchanges and how these are interwoven into the decisions a person makes. I not only have 'lived' experience of being a caregiver but also have shared snapshots of the 'lived' experience of other caregivers. This means that behind the joint production of shared understanding between storyteller, researcher, and the audience (Silver, 2013) will sit my voice that is underpinned by my experiences as outlined above.

Dementia

Dementia is an umbrella term for a chronic condition that activates physical changes in the brain leading to a loss of brain function. The outcome of these physical changes and subsequent loss of brain function translates to significant changes in behaviour, personality, and mood for the person living with dementia (Alzheimers New Zealand, 2019; Timmons et al., 2016). There are many different types of dementia but the four most common are Alzheimers disease, Vascular dementia, Lewy Body disease, and Frontotemporal dementia (Alzheimers New Zealand, 2019).

Some types of dementia have specific symptoms most commonly observed with that type of dementia but there are also symptoms that are commonly shared between the four main dementia types. With physical functioning, the most common symptoms across the four main types are: loss of ability to perform everyday tasks such as washing, dressing, and eating; loss of balance and movement; loss of bowel and bladder control; and wandering. With cognitive functioning, the most commonly experienced symptoms are: confusion, apathy, memory loss, hallucinations and/or delusions, poor judgement, lack of empathy and insight into self (Alzheimers Association, 2020; Alzheimers New Zealand, 2019). Cognitive deficit can also affect speech. When speech is affected, symptoms include lack of speech, repetitive speech, or incoherent speech (Alzheimers Research UK, 2018). Furthermore, a majority of people living with dementia will also experience some type of mental distress such as depression and/or anxiety (Alzheimers New Zealand, 2019; Kitching, 2015; Kwak, Yang, & Koo, 2017). It is important to understand, however, that the symptoms are dependent on which structures of the brain are affected in a particular individual. This means that not all people living with dementia will experience all symptoms that come with this condition nor will symptoms present in a set sequence. Likewise, structures in the brain will be affected at different progression rates in different individuals. In this way, speeds of progression and severity of symptoms will be unique to the individual (Alzheimers New Zealand, 2019; Alzheimers Research, UK, 2018).

Ageing Trends, Dementia, and Caregiving

The main risk factor for dementia is age (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010; Kenealy, 2020). According to Kenealy, in New Zealand (NZ) it is presently estimated that one in 20 people over the age of 65 years will develop dementia, increasing to one in five over the age of 80 years. Additionally, life expectancy in NZ is increasing. The average life expectancy in NZ was 73.8 years in 1936 (Didham & Cheung,

2011). This increased to 83.2 years in 2019 and is projected to rise further to 87.1 years by 2050 (United Nations, 2019). When viewed in context of the number of people in NZ living with dementia this translated to 70,000 in 2019. This number is estimated to rise further to 210,000 by 2050 (Alzheimers New Zealand, 2019). The projected increase in people living with dementia is because increased life expectancy increases the number of people in the 65 and above age groups (Alzheimers New Zealand, 2019; United Nations, 2019).

As the number of people living with dementia increases, so will the number of caregivers required. This is because the majority of people living with dementia will eventually require a full-time caregiver (Andrieu et al., 2005; Brodaty & Donkin, 2009; Soong, Au, Kyaw, Theng, & Tudor-Car, 2020). This is especially true in the later stages of dementia when physical and cognitive deficit becomes more advanced and symptoms increase or become more severe (Alzheimers New Zealand, 2016). Often co-residing companions, partners, or spouses are the first to provide the care required (Brodaty & Donkin, 2009). In NZ, however, caregiving among Māori is frequently perceived as a shared and collective cultural obligation where all whānau are expected to pool resources to provide help (Dudley et al., 2019). Whānau among Māori, however, does not have set boundaries. Whānau can include family members across several generations and/or fostered or adopted members (Collins, & Willson, 2008; Herewiri, 2018). This means it is normative practice among Māori for caregivers to also include extended family members as well as adult children and grandchildren (Collins & Willson, 2008).

Caregivers

Caregivers are individuals who provide varying levels of assistance with both activities of daily living and instrumental activities of daily living. Activities of daily living are the basic daily functions associated with a person's self and body such as dressing, toileting, mobility, and eating. Instrumental activities of daily living include more complex

activities required to function independently within a community such as organising financial transactions and taking medications (Mlinac & Feng, 2016).

A distinction is often made between informal and formal caregivers based on remuneration for care services. Informal caregivers are commonly described as individuals who do not receive an income for their caregiving services whereas formal caregivers are described as paid employees (Paulus, Van Raak, & Keijzer, 2005). Usually, therefore, informal caregivers are partners, family, relatives, neighbours, or friends whereas formal caregivers are health workers such as care attendants and nurses employed by outside care agencies (Roth, Fredman, & Haley, 2015). In NZ, however, some informal caregivers such as parents and family members, can receive a wage through the funded family care benefit although this benefit is not available to spouses, civil union, or de facto partners (Ministry of Health, 2019). This means that in NZ some informal caregivers are paid for their services, which is contrary to the mainstream literature definition.

To establish clarity, a further distinction between informal and formal caregivers is commonly cited. Generally, formal caregivers are usually in the home only on a provisional and transitory basis because their care plan is based on the assessed needs of the care recipient. This means as the care recipient's needs change, the formal caregivers and the services they provide are modified to suit those changes (Lethin, Hallberg, Karlsson, Janlöv, 2015). In contrast, informal caregiving is more constant; with informal caregivers providing care for longer periods because caregiving for the same person or people continues regardless of changes in care needs (Haikio, Sagbakken, & Rugkasa, 2019; Lethin et al., 2015).

As this study focuses on the informal caregiver experience and all participants in the study fulfil the criteria of informal caregivers as defined above, for convenience, hereafter they will be referred to as 'caregivers' with their role defined as 'caregiving'.

The Decision Regarding Residential Aged Care

Supportive in-home formal care is, in most locations, available from local community care agencies. This type of care can include support with both activities of daily living and instrumental activities of daily living. Domestic chores can also be included in the care package, such as vacuuming and changing of bed linens (Age Concern New Zealand, n.d.; Ministry of Health, 2018). In the later stages of dementia, however, with the progression in severity of symptoms this type of formal care may no longer be appropriate for the situation (Gaugler, Yu, Davila, & Shippee, 2014). Formal care, therefore, can be accessed not just for transitory care needs within the home environment but on a more permanent basis where the care recipient permanently transitions to a residential aged care (RAC) facility.

The responsibility for making the decision to transition the care recipient into a RAC facility is often left to the caregiver (Sury, Burns, & Brodaty, 2013). Although a recommendation for RAC from a health professional can have a significant influence (Brindle & Holmes, 2005; Chene, 2006; Ducharme, Couture, & LaMontagne, 2012; Krull, 2013). At the time of making the decision, however, the caregiver evaluates the care needs of the care recipient and their capacity to provide care that meets those needs. Frequently, this evaluation will result in the care recipient transitioning to a RAC facility (Fitzpatrick & Grace, 2019). This evaluation, however, does not occur within a vacuum but is centred within a social context of shared understandings. Part of this context is the socially shared view that RAC facilities are undesirable and unattractive institutions (Bitner, 2019; Löfqvist et al., 2013). This concept has partially evolved from remembered images of the original ‘nursing’ homes (Warburton & Savy, 2012).

Media has also played a significant supporting role in the negativity surrounding RAC facilities by sensationalising stories of substandard care (Jones, 2018; Russell & Nightingale, 2019). Consequently, moving to a RAC facility is considered a last resort, only undertaken

when there is no other option (Cheek, Ballantyne, Byers, & Quan, 2006; McKechnie et al., 2018; McKernan, 2019). Once the decision is made, however, the person living with dementia usually stays in a RAC facility until their death, which creates another transition for the caregiver to navigate (Cheek, et al., 2006; Löfqvist et al., 2013).

Overview of Thesis

Chapter One introduces the study and outlines my position as researcher. **Chapter Two** critically examines the factors described in the literature that influence the decision-making process for transitioning the care recipient into a RAC facility. **Chapter Three** discusses aspects that emerge for the caregiver after the decision for transitioning the care recipient is made. At the end of this chapter is the research question. **Chapter Four** presents the methodology for the study. An outline is provided of the social constructionist epistemology that underpins the narrative approach to the research. Furthermore, a framework for explaining the levels of narrative that informed the analysis is discussed. **Chapter Five** describes the method including procedure, participants, recruitment of participants, and data analysis. **Chapter Six** presents the findings from the narrative analysis. This chapter discusses five narratives; 'This is why I had to'; 'They said I need to'; 'It was a last resort'; 'I made the right decision', and 'This is how I am adjusting'. **Chapter Seven** provides a discussion section that presents an overall summary of the thesis and situates the findings in the literature. Directions for future research and implications for future practice are also offered and considerations relating to the study are discussed.

Chapter 2: Decision For Transition to Care: Influencing Factors

Research has highlighted that permanently transitioning a person with dementia into a RAC facility is a major life changing and challenging event for both the caregiver and the care recipient (Buhr, Kuchibhatla, & Clipp 2006; Rose & Lopez, 2012). To comprehend the significance of this transitional point for caregivers, an understanding of the factors that caregivers evaluate during the decision-making process is required. This chapter, therefore, will explore what literature suggests are the main factors that caregivers take under consideration when making this decision.

Carer Burden and Role Strain

This section will begin by exploring two negative caregiver consequences that are outlined by research as the main contributing factors for the decision to transition the care recipient into a RAC facility. The two negative consequences are commonly referred to as carer burden and role strain. Although carer burden and role strain are based on a negative framework they are still regularly referred to in research as they document part of the caregivers' experience. Because of this, carer burden and role strain have been included in this review.

Research suggests that carer burden happens because of excessive stress and strain experienced by the caregiver because of the caregiving role (Cheng, 2017; Reed et al., 2014; Shaji, George, Prince, & Jacob, 2009). Furthermore, the reason carer burden is frequently viewed as a negative consequence of the caregiving role is because research also connects carer burden to poorer physical and mental health outcomes in caregivers. For instance, a review by Richardson, Lee, Berg-Weger and Grossberg (2013) explored the effects of carer burden on dementia caregivers health. This review recorded that the caregiving role was responsible for higher carer burden. The higher carer burden was described as the reason for the deterioration in both the physical and mental health of the dementia caregiver. When

discussing physical health consequences, Richardson et al., (2013) suggested that increased stress and strain in the caregiving role increased levels of cortisol and inflammatory mediators. These increased levels were the reasons given for a variety of poorer physical health outcomes experienced by caregivers. When describing mental health consequences, Richardson et al., emphasised that stress and strain from the situation created and increased depression and anxiety. In this way, there is a significant amount of research that generalises carer burden as being responsible for various negative physical and mental health outcomes in caregivers.

Research has linked carer burden to many different aspects of the caregiving role but frequently it highlights neuropsychiatric symptoms as the main implicating factor. Neuropsychiatric symptoms include mental or psychological distress such as depression, changes in mood, hallucinations and delusions, and challenging behaviours such as disinhibition, agitation, repetition, and wandering (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Cheng, 2017). Neuropsychiatric symptoms are linked to carer burden because research has shown they create excessive stress and strain for the caregiver (Cheng, 2017; Reed et al., 2014; Shaji et al., 2009). For example, in the research update and critical analysis by Cheng (2017), neuropsychiatric symptoms were cited as increasing carer burden. Cheng, recorded significant changes within the relationship between the caregiver and the care recipient because of neuropsychiatric symptoms experienced by the care recipient. These changes were recorded as creating extra stress and strain for the caregiver, resulting in increased carer burden. Two further studies by Reed et al., (2014) and Shaji et al., (2009) highlighted similar outcomes. Reed et al., while observing the routine care of patients with Alzheimers disease and carer burden, concluded that caregivers experienced amplified stress and strain when neuropsychiatric symptoms were involved compared to when there were no

neuropsychiatric symptoms. This amplified stress and strain was cited as the reason for higher levels of carer burden experienced by caregivers.

Likewise, Shaji et al., (2009) when exploring care recipients' behavioural symptoms, identified neuropsychiatric symptoms as the leading factor responsible for greater carer burden. This was because the neuropsychiatric symptoms made daily life more challenging and difficult for the caregiver to perform caregiving activities. In this way, caregivers' stress and strain increased, heightening levels of carer burden. There is research, however, that disagrees that neuropsychiatric symptoms are the main cause of carer burden. A study completed by Seidel and Thyrian, (2019), which compared carer burden in family caregivers to professional caregivers, concluded that lower burden in family caregivers occurred because of neuropsychiatric symptoms and higher burden occurred because of personal constraints. Personal constraints in this study was measured in terms of caregiver needs versus caregiver responsibilities. Although this study did not agree that neuropsychiatric symptoms increased carer burden it did agree that stress and strain from the caregiving role was responsible for greater carer burden. This study also highlights that although dementia-related symptoms are an important consideration they are not the only consideration. Constraints on the caregiver are also a part of the equation that needs to be explored if a greater understanding of caregiving experiences is to be achieved.

Carer burden also includes role strain, which is identified as excessive difficulty experienced by the caregiver to perform the caregiving role (Burns, Archibold, Stewart, & Shelton, 1993). Givens, Mezzacappa, Heeren, Yaffe, and Fredman, (2014) explored 'role captivity' among women caring for a person with dementia. 'Role captivity' was defined in the Givens et al., study as the caregiver feeling trapped within the caregiving role. This study found that increased caregiver demand because of the increasing number of caregiving activities produced a perception of 'role captivity'. The perception of 'role captivity' was

linked to higher role strain. A similar finding was described by Liu et al., (2017) although the relationship between caregiver demand, 'role captivity' and role strain was ultimately attributed to a poor sense of balancing competing needs by caregivers. 'Role captivity' and 'role overload' (unbalanced amount of competing roles) were also presented in a study by Brodaty and Donkin (2009) as influencing factors for role strain. In contrast, however, the Brodaty and Donkin study suggested other elements as contributing factors for role strain such as financial concerns, adverse life events, health issues, and relationship quality.

Carer burden and role strain are also commonly presented as the foremost major implicating factors for transitioning the care recipient into a RAC facility. Gaugler, Kane, Kane, Clay, and Newcomer (2003) investigated predictors for nursing home entry using data collected about people living with dementia in nursing home populations. The study identified that when carer burden was present then institutional transition for the care recipient was one and a half times more likely than when there was no carer burden identified. A similar outcome was presented by Spillman and Long (2009) in their study that reviewed caregiver stress and strain (carer burden) as predictors for nursing home entry. Spillman and Long concluded that when stress was excessive (burden present) then transition rates of the care recipient into nursing homes increased significantly compared to when there was low carer stress (little or no burden present). Likewise, a review, of caregiver experiences after the care recipient transitioned into a RAC facility was completed by Nikzad-Terhune, Anderson, Newcomer, and Gaugler (2010). This review cited that during the dementia trajectory burden of care and role strain will exceed caregivers resources; therefore, caregivers will have little choice but to make the decision to transition the care recipient into a RAC facility. These studies all emphasise that when carer burden and role strain are present then transition of the care recipient to an RAC facility becomes more likely.

Although there is strong evidence that role strain shapes decisions to transition care recipients into RAC, there is also some conflicting evidence.

A study by Buhr et al., (2006) brings into question if carer burden and role strain are the foremost reasons for RAC as the majority of their caregiving study population chose "my loved one needed more advanced or skilled care than I could provide" (p.57) as being the main reason for care recipients being transitioned into an RAC facility. This suggests that there are other factors outside of carer burden and role strain that contribute to the decision-making process for transition of the care recipient to an RAC facility.

There is also debate as to whether using these terms is an acceptable approach for describing caregivers' experiences (Alzheimers Society, 2018). The main reason that terms such as 'burden' and 'strain' are controversial is that these words imply that the caregivers role is predominately difficult, negative, and burdensome, which ignores and negates positive experiences associated with caregiving (Alzheimers Society, 2018). Positive consequences for the caregiver, however, have also been documented. A study by Quinn et al., (2020), had participants rate how the caregiving role made them feel using a nine-item caregiving scale. Items on the scale included; *useful, good about myself, important, and appreciate life more*. Well-being was assessed by using the World Health Organization Five Well-Being Index. Quinn et al., concluded that when caregivers experienced positive aspects connected to their caregiving role, they had increased levels of well-being.

When the caregiver journey is viewed, however, from a standpoint of either negative or positive consequences a binary is created. As binaries come from a position of providing only two points of reference, they suggest that reality sits in either category (Baer, 2017). Binaries, thereby, produce a reductionist standpoint that simplifies information because they negate any information that sits between the two points (Williams, 2008). In this way, when understanding of the decision-making process for RAC occurs solely because

of a focus on negative or positive consequences for the caregiver, a simplified version is obtained (Baer, 2017). Moreover, it hinders exploration into the development of the outcome, which also diminishes the role of diversity and difference (Baer, 2017).

Diversity and difference are important for understanding a caregivers' journey with dementia because each caregiver will have a slightly different experience. This is because symptoms, environment, past history, cultural beliefs and individual and relationship characteristics are all unique to the individual situation (Alzheimers New Zealand, 2019; Penrod, Hupcey, Shipley, Loeb, & Barney, 2011; Quinn, Clare, & Woods, 2009). This means that if negative and positive consequences are focused on as the main reasons that care recipients are transitioned into RAC facilities, a huge part of the individual story that speaks to the development of making the decision is lost. An example of this is one study that explores the positive impacts of caregiving rather than just categorising a positive outcome for the caregiver. This type of research gives voice to the more ambivalent experiences documented by caregivers. Using a strengths based approach, Peacock et al., (2010) explored positive aspects of the dementia caregiving journey. Peacock et al., documented that caregiving gave caregivers an opportunity to "give back" (p. 640). Giving back was defined as a returning of perceived prior support and caring that the caregiver had received from the care recipient prior to the caregiving role. Caregivers also formed a better and closer relationship with the person with dementia. This study highlights how the nuanced aspects of the caregiving experience are important if insight into the complete picture of dementia caregiving is sought.

Dementia Symptoms and Safety Responses

Care recipients' symptoms increase in severity especially in the later stages of the dementia trajectory (Crawford, Digby, Bloomer, Tan, & Williams, 2014; Lethin et al., 2015). Symptoms that create a safety issue can be physical in nature such as instability, which

heightens the risk of a fall for the care recipient. Symptoms can also be cognitive in nature such as memory loss, which can result in leaving appliances on heightening the fire risk. These types of symptoms leave the caregiver little choice but to put in place protective practices that diminish the risk to personal safety (Crawford et al., 2014; Haikio et al., 2019; Lethin et al., 2015). Commonly, when caregivers formulate a care plan they will not only need to consider their own personal safety and the safety of the care recipient but implement and modify approaches that address those safety concerns (Crawford et al., 2014; Haikio et al., 2019; Lethin et al., 2015; Marins, Hansel, & Da Silva, 2016). In the Haikio et al., (2019) study, dementia and patient safety in the community was reviewed. Protective practices in this study were outlined as practices or approaches that caregivers undertake to minimise or eliminate harm. This study concluded that the caregiver experience was one of constantly being involved in identifying, implementing, monitoring, and modifying protective practices. Moreover, the study documented that caregivers had to implement new approaches or modify existing approaches in line with changes in the care recipient's symptoms.

Similarly, in the grounded theory study by Marins et al, (2016) caregivers narrated that safety measures were always based on current symptoms, which meant they were constantly thinking of new strategies to minimise harm as symptoms changed and evolved in severity. This study also specifically highlighted that frequently, because of changing and evolving symptoms, strategies only usually worked for short periods of time before adaption or new strategies where required. For instance, one caregiver was initially able to prevent the care recipient from wandering outside by hiding the house keys. As the care recipient's cognitive deficit became greater; however, they started climbing out of the windows. The need to frequently adapt or change safety measures was also highlighted in another study that investigated caregivers' reasons for transitioning a care recipient into a RAC facility. In this example, one of the caregivers in the study spoke about their mother. The mother was given

an alarm to use if she had an accident or injured herself. In the beginning this strategy was suitable and worked effectively but eventually as the mother's symptoms progressed in severity, she started pushing the alarm button all the time regardless of whether there was an emergency or not (Kiwi, Hydén, & Antelius, 2017). Caregivers, therefore, as part of the decision-making process for RAC transition, will regularly assess their culpability and capability in being able to keep themselves and the care recipient safe (Crawford et al., 2014; Haikio et al., 2019; Kiwi et al., 2017; Lethin et al., 2015; Marins et al., 2016).

Loss of Alone Time

The need for constant supervision to ensure safety of the care recipient has implications for respite from the caring role. What was interesting about the Marins et al., (2016) study was that it emphasised that the main strategy used by caregivers to minimise harm, was being present. Caregivers can become immersed in the caregiving role when they have to be constantly present and vigilant to ensure the safety of the care recipient. Caregivers also have to be constantly present to provide assistance with activities of daily and instrumental living (Haikio et al., 2019; Marins et al., 2016; Miskovski, 2017; Mlinac & Feng, 2016; Van Wijngaarden, Van Der Wedden, Henning, Komen, & The, 2018; Wilson, 2015). This was highlighted in the study by Van Wijngaarden et al., which aimed at developing effective health care services for dementia. In this study, one caregiver described her experiences of caregiving in the following way, "At one point, I was so busy taking care of him that I had no activities other than him. He was my job and he was my hobby" (p. 16). Another caregiver in the same study described their experience of caregiving as putting themselves on hold (Van Wijngaarden et al., 2018). Research has also shown that even when caregivers tried to maintain distance from the caregiving role, many found that when they were not physically present, mentally their thoughts were still with the care recipient (Moreno-Cámara et al., 2019; Rayment, Swainston, & Wilson, 2018). These findings suggest

that distance in the dementia caregiving role is extremely difficult to maintain. When distance is diminished in this way the caregiver is more likely to lose their individualism becoming solely immersed in the caregiving role (Van Wijngaarden et al., 2018; Wilson, 2015).

Not being able to maintain distance from the caregiving role also diminishes alone time to pursue individual activities or hobbies (Crawford et al., 2014; Van Wijngaarden, 2018). Often before the occurrence of dementia individual activities and hobbies were established patterns of practice. A study by Crawford et al., that encouraged caregivers to talk about their caregiving experiences had caregivers describing how their alone time had changed. One caregiver cited that shopping was no longer enjoyable as she felt the constant need to rush home as she was worried about the care recipient. For this caregiver, shopping had been a relaxing and enjoyable enterprise prior to the caregiving role. Another caregiver in this study enjoyed socialising with her friends prior to the caregiving role, but this had to be severely limited because the caregiving role did not allow time or energy for such activities (Crawford et al., 2014).

Being isolated from friends in the caregiving role is not an uncommon experience. When Van Wijngaarden et al., (2018) explored caregivers experiences of living with dementia, caregivers commonly expressed feeling isolated. There were two main reasons cited in this study as barriers that prevent caregivers from socially interacting with friends. Firstly, it was difficult to arrange day trips to visit friends between activities of the caregiving role. Secondly, friends were often reluctant to visit because they felt unable to deal with the new situation. Besides highlighting how alone time had changed and the reasons why these changes happen the more important outcome of these two studies is that alone time is an important but a commonly unmet need for caregivers (Crawford et al., 2014; Van Wijngaarden et al., 2018).

Caregivers frequently, therefore, feel overwhelmed and exhausted by having to be constantly present to perform the caregiving role. At these times, some caregivers will start to use respite care services (Timmons et al., 2016). Even when respite care is available, a proportion of caregivers will use this time to catch up on routine activities and domestic chores rather than invest the time on themselves for leisure activities (Greenwood, Habibi, & Mackenzie, 2012). Moreover, research suggests that caregivers regularly under-utilise respite care options (Leocadie, Roy, & Rothan-Tondeur, 2018). It is common that caregivers will not be able to access respite care because there are no beds available, they are in an area where respite is not offered, or the level of incapacity that the care recipient experiences will not be suited to the respite care available (Jansen et al., 2009; Leocadie et al., 2018; Plöthner, Schmidt, De Jong, Zeidler, & Damm, 2019; Robinson et al., 2011).

In NZ, it has also been highlighted that there is a lack of quality assurance and monitoring of respite care facilities, which can result in poor quality of care (Synergia, 2019). Nonetheless, when respite care has been utilised, studies have shown positive benefits for the caregiver such as a decrease in carer burden (Vandepitte et al., 2016). Other studies, however, have demonstrated that these benefits are only transient while the care recipient was in respite care (Brodaty & Berman, 2015; Neville & Byrne, 2008). Probably the most compelling evidence for the use of respite care was given by Lee, Morgan, Lindesay (2007) when they described a positive effect on the quality of caregivers sleep while the care recipient was away at overnight respite. When respite care is not used or respite care is no longer sufficient to provide distance or adequate alone time for the caregiver then the option of transitioning the care recipient into a RAC facility becomes more attractive (Neville, Beattie, Fielding, & MacAndrew, 2014; Vandepitte et al., 2016).

Hospital and Emergency Department Admissions

There are a number of causes that bring people living with dementia to hospital and emergency departments. These causes commonly include malnutrition/dehydration, urinary tract infections, general infections, behaviour problems and falls (Bellantonio et al., 2008; Givens, Selby, Goldfeld, & Mitchell, 2012; Nourhashémi et al., 2001). The main reason for hospital admission, however, is not clear cut. A study by Nourhashémi et al., demonstrated that behavioural problems were the main reason for admission whereas Bellantonio et al., advised it was due to falls with or without fractures. In contrast, Givens et al., cited suspected infections as being the most common cause for admissions. This research highlights the variety of dementia-related symptoms and behaviours that create the necessity for hospital visits and admissions.

As there is a large number of dementia-related symptoms and behaviours that can led to a hospitalisation, research is clearer on the frequency of hospital visits and admissions. Hospital and emergency department admissions have been evidenced as being more frequent in people living with dementia than in people without dementia. LaMantia, Stump, Messina, Miller, & Callahan (2016) investigated hospital and emergency department usage patterns among older adults with dementia. They found that people living with dementia visited the emergency department, were hospitalised from those visits, and returned to the emergency departments within 30 days more often than people who were not living with dementia. This research mentioned that their study population had a higher range of co-mobilities; however, it did not investigate if those co-mobilities influenced the hospital and emergency department admissions. Shepherd, Livingston, Chan, & Sommerlad (2019) investigated hospitalisation rates and predictors among people living with dementia. They concluded that people living with dementia had a higher risk of hospital visits and admissions than people not living with dementia regardless of co-mobilities. Additionally, they found that the risk did not increase

with each new co-morbid condition. These findings suggest that people living with dementia will have more interactions with health professionals in hospital settings than people not living with dementia.

In the hospital setting, therefore, frequently health professionals recommend RAC for the care recipient (Brindle & Holmes, 2005; Wilson et al., 2013). When the recommendation is made by a health professional, it usually occurs after a crisis that has led to a hospital admission or a visit to the emergency department (Brindle & Holmes, 2005). This is generally because during a hospital or an acute emergency department admission an assessment of adequacy of care provision is completed. During this assessment if significant risk is identified and/or it is determined that the person's care needs exceed the caregivers' and available community support resources then transitioning the care recipient into a RAC facility is advised or strongly recommended (Brindle & Holmes, 2005; Wilson et al., 2013).

Although health professionals are involved in hospital settings, caregivers and family frequently still retain the sole responsibility for making the decision for transition of the care recipient into a RAC facility. In these situations, however, the hospital admission or emergency department visit can still be an influential factor for making that decision. In a study by Crawford et al., (2014), where caregivers were asked about transitioning the person with dementia into a RAC facility, half of the caregivers cited that the hospital or emergency department admission was the tipping point for making the decision. Many of the caregivers in this study felt that the hospital visit instigated the realisation that they could no longer care for the person at home. This finding aligns with other research that has shown hospital and emergency department admissions are a significant implicating factor for RAC transitions. Bellantonio et al., (2008) advised that the majority of their study population were transitioned to a nursing home after an acute hospital or emergency department admission. Similarly, Knapp et al., (2016) highlighted that prior experience of general hospital and mental health

inpatient care strongly predicted the probability of an admission to a care home. Likewise, the study by Harrison et al., 2017, that attempted to establish predictive factors for discharge to a care home following an acute hospital admission concluded that it was a common occurrence for people with dementia to enter a RAC facility after hospital admission. Interestingly, this study could not establish predictive factors that made this more likely other than the acute hospital admission. All these studies indicate that a person living with dementia will have a higher likelihood of moving to a RAC facility if they enter a hospital setting because of a serious health or behavioural event. This means that hospital and emergency department visits and admissions are major influencing factors for RAC.

The research by Crawford et al., 2014, Bellantonio et al., 2008, Knapp et al., 2016, and Harrison et al., 2017 also brings attention to the need for future care planning for the care recipient. According to Fitzpatrick and Grace (2019) when a caregiver or family meet with a health professional to discuss RAC for the care recipient if a diagnosis of dementia has been made prior to the hospital admission, caregivers are not surprised by the discussion on RAC facilities that ensued as they had already commenced future planning for care needs. Similarly, Afram et al., (2014) found that most caregivers in their study had considered the kinds of reasons that might be important when transitioning care recipients to RAC. For the care recipient these reasons included overall deterioration in condition and endangerment issues and for the caregiver an inability to provide adequate provision of care.

There was a difference between these two studies, however. In the Afram et al., (2014) study although caregivers had considered the reasons that RAC for the care recipient might be necessary, the majority of caregivers in their study had not commenced future planning for it. As this study was focused on the perceived reasons for RAC versus actual reasons for RAC it did not address why this occurred. A study by Dellasega and Nolan (1997) did take into consideration why lack of future planning occurred. This study

interviewed family caregivers who had recently been involved in transitioning the care recipient into a nursing home. Dellasega and Nolan demonstrated that most caregivers did not think about or plan for the transition until a crisis occurred. The study concluded the main reason this occurred was because of the negativity surrounding RAC facilities. The negativity caused caregivers to feel guilty for thinking about or considering RAC, therefore, they did not plan for it. Frequently, the guilt was underpinned and made worse because caregivers could not discuss it with the care recipient. Other barriers to future planning were cited as unfamiliarity and lack of knowledge of RAC facilities, funding, and lack of support.

There are also implications for both the caregiver and care recipient when future planning for RAC is not completed and the care recipient moves into a RAC facility after a crisis. In a time of crisis the environment is already decision-laden and busy, which means that time and energy for complex decision-making becomes limited (Brown, 2012; Dellasega and Nolan, 1997; Fitzpatrick & Grace, 2019). Transition of the care recipient into an RAC is a complex decision as the caregiver has to navigate complicated formal care systems, find funding, and secure a room in a RAC facility (Cheek & Ballantyne, 2001; Fitzpatrick & Grace, 2019). In a situation where time and energy are limited, making this type of complex decision can mean the caregiver may rush their decision-making process; therefore, not be able to properly evaluate all options. A decision made in this way can mean that the first bed that becomes available is chosen even when the RAC facility is not deemed as the most suitable by the caregiver (Brown, 2012; Fitzpatrick & Grace, 2019). This section highlights there are adequate reasons why RAC for the care recipient is likely to be an option in the future and why it is not ideal to implement in a crisis situation. This means that future planning for RAC for the care recipient is an important consideration for caregivers.

The Role of The Health Professional

Health professionals play an important role across many services that people living with dementia and their caregivers' access. For example, these interactions might include a home visit from a social worker or a visit to a doctor in a local medical centre. It is not uncommon for people within such roles and settings to make recommendations around transiting someone living with dementia into a RAC facility (Chene, 2006; Ducharme et al., 2012; Krull, 2013).

Health professionals have been reported by caregivers in some research as lacking in 'helpfulness' (Chene, 2006; De Vreese, Salvatore, Rovesta, & Fabbo, 2016; Teng et al., 2020). The caregivers in the study by Chene, which investigated dementia and transitions to RAC indicated that caregivers felt a lack of support from health professionals as very little information for and help with managing transitions to RAC was provided. A similar finding of 'unhelpfulness' was found by De Vreese et al., when they reviewed relevant research. This review emphasised that health professionals frequently stepped back from dementia care planning because they lacked the ability to supply accurate information and comprehensive current and future care plans.

Just as commonly, however, caregivers have found the support, advice, and encouragement from health professionals invaluable (Ducharme et al., 2012; Krull, 2013). In an interview study by Krull (2013) caregivers were asked about the role that their doctor played in the process of their decision-making regarding RAC. They described how the doctor's recommendation for RAC was the 'push' that they needed to make the decision. Caregivers spoke about the 'push' as a cementing of what they already knew was necessary but were unable to put into practice without the doctor's endorsement. Similarly, the Ducharme et al., (2012) study that explored the role of health professionals in the decision-making process, interviewed caregivers. Some of the interviews highlighted that the local

doctor's and social worker's evaluations that assessed RAC as necessary, justified and legitimatised the acceptability of transitioning the care recipient. This allowed the caregivers to move forward and make the decision without guilt. The Krull and Ducharme et al., studies highlight the importance of the role of health professionals in helping caregivers with the decision-making process for transitioning the care recipient into RAC.

This research suggests that the role of the health professional can be both helpful and unhelpful. One aspect that is highlighted as contributing to whether health professionals are or are not helpful with their recommendations for RAC, is the competency of their knowledge of dementia (Chene, 2006; De Vreese et al., 2016). De Vreese et al., describe local and family doctor's as being in a unique position to make an accurate assessment of the situation for RAC because often they have a long-standing association with the person involved. According to De Vreese et al., local and family doctors, however, require proficient knowledge of all aspects relating to the dementia environment to supply an accurate and well-trained assessment of the situation. Likewise, Chene (2006) detailed that social workers in the health care sector are favourably positioned to assess the caregiver situation when the care recipient is being assessed. Chene (2006), however, concluded that the assessment needs to be from a well-trained person who understands not only dementia but the implications and consequences for the caregiver managing this condition. The caregivers in this study were shown to have greater confidence in the social worker's assessment for RAC when this was the case. This research confirms that when it comes to assessments for RAC, for caregivers to move forward with these recommendations they need to feel secure that the assessment is correct. The way that caregivers achieve this security is by believing that the health professional had the appropriate knowledge and training to make the assessment in the first place (Chene, 2006; De Vreese et al., 2016). When the caregiver trusts the health

professionals recommendation then that recommendation can become a significant influencing factor for RAC for the care recipient.

Physical Health of the Caregiver

Caregivers experience physical illness and injuries like all people. One difference for caregivers is that when they are physically sick or injured, they still have the responsibility of taking care of another person, providing support with activities of daily living such as showering and dressing (Mlinac & Feng, 2016). To be able to fulfil their role with these types of activities caregivers' require a certain level of physical competency (Cranwell, 2016). When sickness or injury compromises the caregivers level of physical competency, then a caregiver maybe unable to continue in the caregiving role. This was highlighted in a meta-analysis by Couture, Ducharme, Sasseville, Bradette, and Gaudet (2020), which explored caregivers' reasons for transitioning the care recipient into an RAC facility. Couture et al., documented that caregivers, when sick or injured, evaluated their ability to support the care recipient. If caregivers decided that due to their health they were unable to sufficiently provide competent and safe care, then commonly a decision for RAC was made.

In agreement, the study by Ducharme et al., (2012) that investigated the decision-making process of family caregivers regarding RAC also highlighted that a contributing factor was the caregivers' physical health. When the caregiver's physical resources were compromised, they evaluated their performance as caregivers. If care was deemed insufficient, then the likely outcome was that the care recipient moved to a RAC facility. Similarly, when caregivers were asked to pick one of five reasons for transitioning the care recipient into a RAC facility in a study by Buhr et al., (2006) half of the participants cited that their health was the reason they could not continue in their role and the transition was necessary. In these instances, research has shown that physical sickness or injury for a

caregiver has implications for the decision-making process of RAC, which highly influences the outcome.

When a caregiver becomes sick or injured the option of transitioning the care recipient into RAC sometimes, however, moves beyond the caregivers control. When an evaluation of reasons for nursing home transition by spouses was completed by Kraijo, Leeuw, and Schrijvers (2014) they documented that calamities often necessitate emergency transitions where caregivers have no option but to agree with transitioning the care recipient into a RAC facility. Even in situations where the transition is intended to be short term respite for the caregiver, extended periods of rehabilitation or complications following ill health can mean that respite care becomes the beginning of a permanent care transition. Thus the situation moves beyond the control of the caregiver rather than coming about as a decision influenced by their own assessment of their health needs and the impact of this on the provision of care.

Funding

Part of the process of transitioning the care recipient into a RAC facility can be the requirement to obtain funding. In New Zealand, RAC is subsidised by a residential care subsidy through Work and Income. The residential care subsidy is based on an assessment of need (Work and Income, n.d.). The result is that unless the care receiver is assessed as having high or very high needs and cannot be safely cared for at home, they are not entitled to entry into a subsidised RAC facility (Age Concern, n.d.). Additionally, the residential care subsidy is also asset and income tested (Work and Income, n.d.). This means that if the informal caregiver and/or care recipient have assets or income in excess of the limit then no subsidy is available.

Another consideration with funding is that only RAC facilities that have a contract with the local District Health Board (DHB) will supply the benefit of a maximum

contribution cut-off. In some areas in NZ, especially rural areas, DHB contracted RAC facilities are not available (New Zealand Aged Care Association, 2010). If the RAC facility is not contracted to the DHB then the amount an individual has to contribute has no restriction (Age Concern, n.d.). In 2017, it was assessed that 11,070 NZ residents had assets outside the threshold allowed for receiving a residential care subsidy (Ministry of Health, 2017). In 2020 this group of people would be paying the entire maximum contribution, which is based on the current average RAC facility pricing, ranging from $1096.48 to $1193.08 per week (Bloomfield, 2020). Funding and DHB regulations, therefore, have implications for access. If the care subsidy or a DHB funded facility is not available then an individual may have to make a trade-off between necessity (what is affordable and available) and what they consider is the most ideal or suitable RAC facility for the care recipient (Davies & Nolan, 2003).

The Social Context of RAC Facilities

There is a widely held view of RAC facilities believed by community-based dwellers that RAC facilities are unattractive places that lack vibrancy (Bitner, 2019; Löfqvist et al., 2013). These less than stimulating institutions are also thought to reduce autonomy and freedom (Löfqvist et al., 2013). Information on how lack of vibrancy can occur was presented in a study by Bitner (2019) that included a description on the internal design of RAC facilities. In general, RAC facilities are unlike home environments where there is an individual design to suit the occupant. In an RAC facility there is a prevalence for a generic structure that provides a bland monochromatic landscape. This occurs mainly because of financial restraints and consideration for ease of management for staff to provide care. According to Bitner, however, it is not just the generic landscape that decreases vibrancy but the generalised monotony of daily routines, where everyone completes the same task at the same time in the same way. In this way, Bitner suggests that the public perception of RAC

facilities as lacking vibrancy is connected to the structural layout and routines provided by RAC facilities.

When an RAC facility provides this type of generalised structure and routine, individual autonomy and freedom are also challenged. Löfqvist et al., (2013) explored older people's reflections on relocating to an RAC facility. Participants in this study believed that if they moved into a RAC facility their autonomy and freedom would be lost. Participants described this as occurring because they would no longer be able to make decisions about their daily routines and would have to conform to fixed schedules as supplied by RAC management. This perception of life within an RAC facility led to participants believing that RAC facilities were unstimulating and undesirable places to live. They are viewed as places that you only enter if you have no other choice because you are at the end of your life and unable to care for yourself (McKechnie et al., 2018; McKernan, 2019).

The perspective that RAC facilities are undesirable places that reduce autonomy and freedom has also partially developed from remembered images of the original dementia 'nursing homes' (Warburton & Savy, 2012). This type of RAC was designed to keep sick older people away from healthy and productive younger people because the ideology at that time was that when older people became incapacitated, they were burdensome and of little value to society (Cusack & Thompson, 2013; Thorson, 2013). Care models in these nursing homes were also underpinned by the same ideology; therefore, care generally included keeping 'patients' docile and complaint, with residents frequently being restrained and/or given drugs such as antipsychotics (Croucher et al., 2011; Rosenzweig, 2012). In this type of care there was no accommodation for autonomy or freedom (Rosenzweig, 2012).

Today, dementia facilities are starting to change to an ideology of 'assisted and/or person centered living' rather than a fully 'structured living' model. Assisted and/or person centered living supports independence and agency through fostering individual activities that

provide vibrancy, motivation, and purpose (Peters, 2020; Rosenzweig, 2012; Scott, Webb, & Kostelnick, 2018). The legacy of the old 'nursing homes' care model; however, still remains and adds to the negativity surrounding RAC facilities. An attractive and stimulating environment that provides autonomy and freedom are important concepts for older people (Löfqvist et al., 2013). When RAC facilities are perceived as a barrier to those concepts then it is unlikely, they will be utilised unless absolutely necessary (McKechnie et al., 2018; McKernan, 2019).

The public perception that RAC facilities should be only utilised as a last resort is evident in NZ. RAC facilities in NZ are mostly utilised for hospice type care where people remain in permanent care until their death rather than for rehabilitative or convalescent purposes (Broad et al., 2015; Connolly, Broad, Boyd, Kerse, & Gott, 2013). RAC facilities being used only for permanent care until death highlights the strength of the view held by community-based dwellers that these places should only be used as a last resort option (Cheek et al., 2006; Ryan & Scullion, 2000; Warburton & Savy, 2012).

RAC facilities are also commonly represented in the media from a negative standpoint. The media tend to sensationalise topics to engage and polarise their readers (Doyle & Roberts, 2017; Miller, Tyler, Rozanova, & Mor, 2012; Rozanova, Miller, & Wetle, 2014). Stories of abuse and neglect of people living in RAC facilities fall into this category whereas stories that people are happy living in care and/or that this was the right option for their caregivers, does not. When positive stories of RAC facilities are absent then the stereotype that RAC facilities only provide 'problematic' care is highlighted. The more this is brought to the notice of the general public the more it becomes a shared view in society (Doyle & Roberts, 2017; Miller et al., 2012; Rozanova et al., 2014). Media in NZ is no different, often providing stories relating to issues of incompetency that have led to inadequate provision of care (Jones, 2018; Russell & Nightingale, 2019).

Additionally, a report by two NZ political parties provided a review on RAC facilities that agreed with media stories of inadequate provision of care. The review highlighted that RAC facilities provide an institutionalised universal approach where everyone is catered for in the same way. This way of operating was connected by the report to providing a less than ideal standard of care. The report, therefore, recommended that if standard of care in RAC facilities was to be deemed acceptable it needed to be changed to a person-centred approach where individual needs are identified and accounted for (New Zealand Labour Party & Green Party of Aotearoa New Zealand, 2010).

As this report was completed by two political parties it may have been influenced by their own political agendas. The report, however, is presented in an official capacity by an authoritative body, which adds credibility to what the report is presenting (Searing, 1995). In this way, the report ratifies that the one sided negative story of RAC facilities reported by media outlets is not without substance. Through sources such as these, NZ caregivers' perceptions of RAC are shaped. It will, therefore, be difficult for caregivers to make the decision to transition the care recipient into a RAC facility when they believe that all RAC facilities provide less than ideal living situations and/or substandard care.

Chapter Summary

This chapter highlights that there are diverse factors that are considered by the caregiver during their evaluation of transitioning the care recipient into a RAC facility. Some research concentrates on negative and positive consequences of the caregiving experience to explain the outcome of RAC. The factors that are outlined by this type of research do still form part of the caregiving experience, therefore, to exclude them would mean excluding both the difficulties that caregivers have to navigate and the more favourable aspects of the caregiving role. Furthermore, this type of research does highlight one important aspect, impacts for the caregiver are frequently dependant on a care recipients symptom trajectory.

Focusing on these aspects, however, overlooks the nuanced and ambivalent details of the decision-making process, which are important for a comprehensive representation of this transitional point. The minutiae of the day to day experience that is explored when caregivers' own voices are acknowledged bridges this gap. For instance, when 'role captivity' is objectively identified as a factor, it is not until a caregiver explains in their own voice that alone time is impossible because their sole daily focus is attending to the care recipient's needs that the finer details of the situation are revealed (Van Wijngaarden et al., 2018). Furthermore, when several voices are acknowledged, diversity and difference are recognised, which are important elements for understanding the dementia caregiving experience (Alzheimers New Zealand, 2019; Penrod et al., 2011; Quinn et al., 2009). In this way, research demonstrates that caregivers evaluate their unique situation by assessing a variety of factors that are interwoven together rather than individual factors.

Research has also outlined that the evaluation of the situation prior to transitioning a care recipient into a RAC facility is not always based on the caregivers' sole judgement of the situation. Caregivers and care recipients are frequently involved with a variety of professionals involved in dementia care. During these times, the home situation and/or caregivers or care recipient's health can be assessed. Assessments frequently lead to recommendations for RAC, which influence the caregiver towards the decision to transition the care recipient into a RAC facility (Bellantonio et al., 2008; Harrison et al., 2017; Knapp et al., 2016). In some circumstances, caregivers may also have little choice in transitioning the care recipient to a RAC facility. This can happen when the caregiver is no longer in a position to continue in the caregiving role (Kraijo et al., 2014). Often, therefore, the decision for RAC is based on an assessment of the situation by not just the caregiver but in accordance with health professionals' recommendations.

The factors presented in this chapter are not experienced in isolation of each other. They are also not experienced in isolation from the social world. The wider social context that provides shared meanings and understandings of RAC underpins any decision for transitioning the care recipient. It is difficult for caregivers to overlook constant media that delivers a negatively presented view of RAC facilities. When these reports are represented in an official manner, they suggest authority on the subject, which only reinforces the already established negative outlook of RAC facilities. Caregivers take this information and form an understanding that RAC should therefore, only be utilised when no other option is available.

Chapter 3: After the Decision

Caregivers lives continue after the decision to transition the care recipient into a RAC facility is made. Eventually, during this period caregivers will also experience the death of the care recipient. This section, therefore, will explore what are the main factors, highlighted in literature, that contribute to the caregivers' experience of life after the decision for transition of the care recipient to a RAC facility is made.

Accounting for the Decision

In retrospect, after the decision to transition the care recipient to a RAC facility is made, caregivers frequently feel guilty that they could have done better in their 'duty of care' and kept the care recipient at home for longer. To alleviate this guilt caregivers frequently feel the need to justify their decision (Jackson & Gaugler, 2015; Kwon & Tae, 2012; Ryan & Scullion, 2000). When Kwon and Tae explored the adaptation of adult children caregivers after the decision to transition a parent into RAC, they observed that justification was a frequent strategy utilised by caregivers to come to terms with this decision. Caregivers experienced guilt because they felt they had 'abandoned' the care recipient into a place that was an adequate but less than a desirable option. According to Kwon and Tae, the frequent justification for their decision was to receive reassurance from other people that the decision that they had made was the correct one. In the Kwon and Tae study, justification was achieved by caregivers through highlighting the advantages of nursing homes such as care recipients were well feed, kept clean, and kept safe.

Likewise, in Jackson and Gaugler's research on long-term care in an ageing society, caregivers acknowledged that commonly they felt they had 'let down' the care recipient when the decision for RAC was made. Several caregivers in this study described feeling that they should have been better in their role as a caregiver and kept the care recipient at home for longer. In this way, caregivers felt they had 'failed' the care recipient. Underpinning the

feeling that as a caregiver they had failed, was the belief that an RAC facility for the care recipient was a less than ideal place to live (Jackson & Gaugler, 2015). This study concluded that this was the main reason why caregivers justified their decision by telling other people they had validation from a doctor that the care recipient was unfit to remain at home. Similarly, when transitioning care recipients into nursing homes was explored by Ryan and Scullion (2000), they observed that caregivers also justified their decision in retrospect. After the decision, caregivers felt guilty about their performance and about transitioning someone into an environment that they deemed less than ideal. Caregivers in the study by Ryan and Scullion, however, justified their decision by emphasising that friends and family had shared in the decision-making-process and in most situations, had agreed transition of the care recipient into a RAC facility was necessary. All these studies highlight that caregivers can experience a sense of guilt after the care recipient has transitioned into a RAC facility. Commonly, this guilt is underpinned by the negative view of RAC facilities. To alleviate the guilt, caregivers justify their decision by citing evidence that the transition of the care recipient into a RAC facility was absolutely necessary (Jackson & Gaugler, 2015; Kwon & Tae, 2012; Ryan & Scullion, 2000).

Filing the Gap

Caregivers, especially where there has been a long-term caregiving relationship experience a ‘gap’ when the person with dementia dies (Corey & McCurry, 2017; Larkin, 2009). Caregiver experiences of life after the death of the person with dementia was explored by Corey and McCurry. Caregivers in this study explained that there were several reasons for the perceived emptiness experienced after the death of the care recipient. Firstly, after being a caregiver for so long it was difficult to adjust to a role that did not involve caregiving activities. Caregivers advised that it was hard to decide what to do with all the time and energy that was previously spent on visiting the care recipient in an RAC facility and on

activities that catered to the care recipient's needs. Secondly, caregivers experienced an aloneness that had not totally existed before when the caregiver was still able to visit the person with dementia in RAC. Lastly, it was difficult to figure out how to live again solely for oneself (Corey & McCurry, 2017).

The perceived emptiness, therefore, is partially connected to a sense of identity and purpose. When caregivers become immersed in the caregiving role, their identity can solely become that of a caregiver, with their purpose being caregiving (Wilson, 2015). When the caregiving role ends these caregivers lose the ability to define who they are and what their purpose is (Larkin, 2009). When Larkin (2009) studied the post-caring experiences of former carers this experience of loss of identity and purpose was likened to a loss of equilibrium by several caregivers. They spoke of being "all at sea", "at a standstill", and "an astronaut without gravity" (p. 1032). Supporting this, Jacobs (2006) explored adult children caregivers' experiences after the death of the care recipient and cited caregivers as feeling empty, lost, confused, and unsure of their place in the world during this time.

In contrast, however, some caregivers, found filling the 'gap' was easier. Caregivers achieved this through several different pathways. Some caregivers returned to familiar patterns such as going back to work, focusing on social connections with friends and family, or resuming activities or hobbies that they once enjoyed (Larkin, 2009). Other caregivers wanted to stay in the caregiving role so returning to work included returning to a caregiving role either paid or unpaid. Likewise, another group of caregivers wanted to share the valuable knowledge they had acquired during caregiving and chose to become an advocate for dementia by facilitating groups, writing, and public speaking. Lastly, other caregivers intentionally commenced new sporting, community, or educational activities or fulfilled life-long ambitions such as travelling (Corey & McCurry, 2017; Larkin, 2009). In this way, caregivers created new routines in their lives. The new routines provided purpose and helped

establish new social connections. The new routines and social connections; therefore, helped the caregivers with their sense of identity as it told a story of 'who I am' and 'where I belong in the world' (Larkin, 2009).

Chapter Summary

Commonly, caregivers experience guilt after making the decision to place the care recipient into a RAC facility. The guilt is founded on a perception that their performance has been substandard to their perceived ideal (Jackson & Gaugler, 2015; Kwon & Tae, 2012; Ryan & Scullion, 2000). The perceived ideal that underpins this is that caregivers should have been able to stay in the caregiving role for longer, thereby, being able to keep the care recipient at home rather than transitioning them to a RAC facility (Jackson & Gaugler, 2015). Caregivers come to this conclusion because they believe RAC facilities are a less than ideal living option for the care recipient (Jackson & Gaugler, 2015; Kwon & Tae, 2012). When this perception is held, caregivers frequently use the strategy of justification where they account for their decision. When caregivers validate their decision as necessary and correct, then guilt is alleviated (Jackson & Gaugler, 2015; Kwon & Tae, 2012; Ryan & Scullion, 2000).

Eventually the caregiving role ends when the person with dementia dies in the RAC facility. The caregiving role previously took up much of the caregivers' time through activities such as visiting and catering for the care recipient's needs in the RAC facility (Corey & McCurry, 2017) Afterwards, caregivers find they are now responsible only for themselves and have unaccounted for time where they are no longer busy (Corey & McCurry, 2017; Larkin, 2009). In this way, a 'gap' in the caregiver's life forms.

For many caregivers, however, the 'gap' can be filled by returning to familiar patterns of activity or through implementing new activities (Corey & McCurry, 2017; Larkin, 2009). Whatever way a new routine is established; it provides purpose and helps the caregiver create

a new identity outside of caregiver. The new routines also provide connection to the social world that helps support the caregivers to move forward after the care recipient's death (Larkin, 2009).

Research question

For dementia caregivers, making the decision to transition the care recipient into RAC is a complex, challenging, and difficult decision. Prior to and after the decision, caregivers typically experience many challenges and changes in their lives as well as opportunities for growth. A greater understanding of these experiences is required in order to better represent and support families affected by dementia. In NZ, however, there is little research available that investigates, from a caregivers' perspective, transitional processes in the later stages of dementia such as transitioning the care recipient into a RAC facility and the subsequent death of that person. To address this gap in research, this project will answer the following questions:

1. What is the caregiver's experience of making the decision for transition of the care recipient into a RAC facility?
2. What is the caregiver's experience after transition of the care recipient into a RAC facility?
3. What is the caregiver's experience after the subsequent death of the care recipient?

Chapter 4: Methodology

This thesis will address the above research questions using a narrative approach. A narrative approach allows for examining both experiential processes and the meanings attached to those processes. A narrative approach, therefore, provides a framework for this thesis that permits a thorough exploration of the caregivers' stories of being a caregiver in the later stages of their care recipient's journey with dementia. Furthermore, a narrative approach to the stories caregivers told will highlight how decisions by caregivers were structured and contextualised by the care recipient's symptom trajectory and wider social messages about informal care relationships, responsibilities to care, and RAC facilities. This section will begin with outlining the epistemology that underpins the narrative approach.

Epistemology and Social Constructionism

Epistemology is the theory of knowledge that underpins the theoretical position of the methodology and methods section in research. Epistemology, therefore, is the foundation point for deciding where knowledge comes from and how it presents within human existence and experiences (Crotty, 1998). Crotty advocates for taking a specific epistemological standpoint to justify the methodology and methods section. This allows for in-depth analysis by providing context and a grounding of assumptions that makes those assumptions explicit. Accordingly, different epistemological positions of knowledge create different frameworks for the way research is completed and the outcomes that arise from that research.

Prior mainstream research was dominated by a positivist and empiricist approach (Breen & Darlaston-Jones, 2010). Both positivist and empiricist approaches advocate that by measuring observations of behaviour an absolute objective 'truth' can be determined (Packer, 1985). To determine this 'truth', cause and effect relationships are established by examining individual elements in isolation to each other independent from historical, social, or cultural contexts (Breen & Darlaston-Jones, 2010; Burr, 2015; Packer, 1985). When historical, social,

or cultural contexts have been isolated in this way, an individual's full experience and understanding of an event is often marginalised or silenced (Burr, 2015). In contrast, according to Burr, social constructionism is an epistemology that challenges a positivist and empiricist approach by arguing for scepticism of the dominant absolute reality presented by this type of research. Social constructionism does this by inviting critical exploration into a person's knowledge of the world while challenging the assumption that it is from an unbiased observation of the world based on conventional knowledge (Burr, 2006). Social constructionism challenges taken for granted knowledges that are by-products of dominant research and social, moral, political, and economic structures (Burr, 2006; Burr, 2015). Social constructionism takes this position because it recognises that human knowledge is influenced by, sculpted from, and replicates historical, political, cultural, and moral dynamic forces that are negated by objective research (Burr, 2015).

Rather than objectively looking for reality in the world, social constructionism centres reality as subjectively coming into existence through shared social processes and interchanges (Burr, 2006; Burr, 2015; Efran, McNamee, Warren, & Raskin, 2013; Galbin, 2014). Social constructionism, therefore, incites critical examination of how knowledge is constructed through social processes and interchanges and becomes 'truth' within the world that a person lives in (Burr, 2006; Burr, 2015). Furthermore, social knowledge and action are interwoven. When understandings are socially negotiated, numerous possibilities for action take place while some patterns of action are sustained and others are excluded (Burr, 2006).

To be able to examine the subjective reality of knowledge in a relational context social constructionism centres language as a vital component (Bo, 2015; Galbin, 2014; Umeogu, & Ifeoma, 2012). According to Bo, language is a social phenomenon that allows for communication where feelings can be expressed, courses of action decided on, and social understandings cemented for future generations. Galbin, however, debates whether language

is merely about communication. Galbin (2014) argues that language is an interactive process that helps a person subjectively interpret the world and their own identity within that world. Similarly, Umeogu and Ifeoma (2012) emphasise that there is no such thing as an innocent word, as all words have meanings that are subjectively analysed and decided on by individuals and groups.

Narrative Psychology

Narrative psychology is underpinned by a social constructionist epistemology. Narrative psychology is a framework for organising peoples' experiences and the meanings that they attach to those events (Riessman, 2008). Narrative structure comes naturally to people as throughout their lives they have learned to be story tellers from listening to other peoples' stories (Wong & Breheny, 2018). Story telling for people, however, is not a passive or benign enterprise rather people connect events into a sequence that is not only important for resulting actions but for conveying meanings that the speaker wants the listener to hear (Riessman, 2008).

People also are drawn to sequencing stories to provide coherence and control of their experience especially when stories of their ideal experience and subjective experience are in conflict (Bruner, 1990). Narrative psychology, therefore, is interested in the whole of the story while examining the sequence of ordered events through a beginning, middle, and end (Riessman, 2008) to attempt to gain an understanding of the structure, function, meaning, and content of the story (Murray, 2003).

Stories, however, are not just a person's own invention as they reflect broader narratives of social life, which are formed from social, political, historical, and cultural influences (Wong & Breheny, 2018). This means that while the stories are personal the underpinning structures that inform the stories are created from shared dominant and taken for granted understandings (Murray, 2018; Riessman, 2008). These understandings also

implicitly hide rules for reacting to and interacting socially within the world (Crossley, 2008). Stories, therefore, give us insight into unspoken rules based on absorption of broader narratives of social life that are a part of our previously formed consciousness and identity (Crossley, 2008; Murray, 2003). Narrative psychology, therefore, focuses on uncovering the implicit narratives and rules as they affect why, how, and which stories are told (Silver, 2013; Wong & Breheny, 2018). Through this process, we can examine both how people construct their identity and point to the forces that structure their world (Feldman, Sköldberg, Brown, & Horner, 2004; Murray, 2003).

Structured Approach to Narrative

Narrative psychology is a broad theoretical approach utilised in several areas of research such as anthropology, sociology, and psychology (Bold, 2011). While narrative psychology provides a broad theoretical framework for understanding and considering peoples' experiences and the meaning they attach to those experiences it needs to be acknowledged that it is not a method with a set of specific instructions for doing analysis (Stephens, 2011). There is, in fact, no one definitive method for narrative analysis because different authors provide different ways of analysing narratives, all of which fall under the umbrella of narrative psychology (Polkinghorne, 1995; Wong & Breheny, 2018).

One of these authors, Michael Murray (2000) proposed a structured approach that makes the analysis process explicit. By providing a structured approach it helps outline to the reader a researcher's rationale for arriving at the narrative analysis they present. This is necessary as narrative analysis is a joint venture between the storyteller, the interviewer, the researcher, and the intended audience, none of which are neutral participants (Silver, 2013). The storyteller will be influenced by who the story will be told to, what questions are asked, and what their own knowledge beliefs and values are. Likewise, the interviewer and researcher will interpret the data through their own lens that is based on their own

assumptions, belief's, and biases (Silver, 2013). Finally, the audience will fill in the gaps in any story through their own established social narratives (Murray, 2008; Silver, 2013).

While, narrative psychology recognises that the knowledge produced is always value-laden, Murray advises that the analysis must be a carefully intentional and reflective process rather than a process based on instinctual and intuitive reflexes. For this to occur, Murray (2000) puts forward four levels that narrative operates out of: personal, interpersonal, positional, and ideological. At the personal level, people tell stories about their experiences and through these stories they convey and define their identities. Furthermore, through stories people make sense of and bring order to the events of their lives within and since the experience (Murray, 2000; Stephens & Breheny, 2013). At the personal level, people also link their stories to a wider social order (Wong & Breheny, 2018). At the interpersonal level, the construction of narrative is positioned as a joint venture where the researcher recognises that there are two people involved in a conversation with a possible orientation to a wider audience (Stephens & Breheny, 2013). At the positional level, the analysis includes consideration of the wider social context of narratives and the social and moral functions of the narrative (Stephens & Breheny, 2013) It is an extension of the interpersonal level where differences in social and moral positions that may influence the stories that are told need to be examined (Murray, 2000; Stephens & Breheny, 2013). For instance, when a healthy researcher interviews a sick person because the person does not want to be seen as a habitual complainer they may shape their story to appear more worthy and fit (Murray, 2000). Lastly, at the ideological level the analysis focuses in on broader social systems that exert influence through dominant shared beliefs and taken for granted understandings, within which narratives are embedded (Murray, 2000; Stephens & Breheny, 2013).

These 'public' narratives can shape what content is included in a story and the moral position that the person takes within their story (Stephens & Breheny, 2013). The framework

that Murray (2000) has provided gives guidance to a researcher. The framework, however, is not intended as a guide for a researcher to use the components individually as the creation of meaning is influenced by all these levels all of the time (Murray, 2000). In fact, in narrative analysis, it is the way these levels can and do work together that is of interest (Stephens & Breheny, 2013).

Social Constructionism, Narrative and Caregivers' Experiences

As social constructionism is concerned with the formulation of a person's subjective reality within a relational context (Efran et al., 2013; Galbin, 2014) it makes it an appropriate platform to explore the journey that a caregiver has with the care recipient. Caring does not happen in solitude but is a relational activity not only with the care recipient but to wider social environments, structures, and institutions (Breheny, Horrell, & Stephens, 2019). On a personal level caregivers' stories will provide a sequencing of their experiences in relation to the care recipient while providing insight into their own identity and role (Tretteteig, Vatne, & Rokstad, 2017). On a wider social level caregivers on a daily basis can have contact with several health professionals, people in similar situations, home care assistants, governing bodies, friends and neighbours, family, and RAC facilities (Fitzpatrick & Grace, 2019; Kiwi et al., 2017; Lethin et al., 2015). Both on a personal and social level a caregiver's subjective reality of the caregiving experience is shaped through these relational interactions.

Additionally, social constructionism is a suitable framework for exploring caregiving trajectories as it focuses on language as a central tenet in situating subjective reality within a relational context (Bo, 2015; Galbin, 2014; Umeogu & Ifeoma, 2012). As caregivers' accounts are centred around the person they are caring for language, is a vehicle to give meaning to the experience and events that are occurring (Miskovski, 2017; Van Wijngaarden, 2018; Wilson, 2015). This centres language not only as being a necessary ingredient but also as a purposeful and intentional activity that not only supports the person using it but the

relationship within which it is being used (Ortlieb & Cheek, 2013). The assessment of language within the caregivers' journey is, therefore, an important medium for investigation.

The use of narrative psychology becomes relevant when it is recognised that caregivers use stories as a way to make sense of their experiences while portraying meaning to the listener (Stephens, 2011). Often caregivers' experiences can be complex, confusing, and diverse while generally situated in a state of constant flux (Zarit & Talley, 2013). Caregivers, therefore, use stories as a method of sequencing events so that their changing reality can be understood, justified, and reconciled (Stephens, 2011). Furthermore, personal stories help a caregiver to identify and define their own unique experiences of caring and what meaning that caring has for them (Tretteteig et al., 2017). Stories, however, are developed not just from the experience; caregivers draw on previously held cultural and historical understandings, beliefs and values to inform their stories, structure, content, and function (Murray, 2000; Wong & Breheny, 2018). Narrative psychology allows for an in-depth analysis that uncovers the implicit that sits within the caregivers' story by identifying what social forces and structures influence the caregiver to tell that story at that time and in that way (Silver, 2013; Wong & Breheny, 2018). Viewing the story through this lens allows for a fuller picture of caregivers experiences before and after making the decision to transition the care recipient into a RAC facility.

Chapter 5: Methods

Procedure

This study analysed in detail interviews conducted as part of a NZ study investigating changing sleep experiences of informal carers of people with dementia (Gibson, & Gander, 2020). The original study was conducted by the Sleep/Wake Research Centre at Massey University to explore changes to sleep across the dementia care trajectory. The original study aimed to understand sleep changes in more detail and across the transition to care. This project had Massey University Human Ethics Approval (16/CEN/101) (See Appendix A). Participants in this original study were recruited from a research mailing list of a prior postal survey study concerning sleep, health and wellbeing. Five hundred and twenty-six participants took part in this survey. Part of the survey included a section for people to complete if they were willing to participant in follow up interviews for the original study. Twenty participants were selected for the original study from that call out (See Appendix B and Appendix C). Twenty semi-structured interviews were conducted with those participants (See Appendix D). At the time of the interviews the care recipient had transitioned into a RAC facility within the last two years and some participants had experienced the bereavement of that person. The semi-structured interview format was chosen to allow participants space to describe their experiences in detail. Interviews lasted from 28 to 77 minutes. Thirteen interviews were conducted face-to-face in the participant's home with the remaining seven participants, who lived rurally, completing telephone interviews. The decision to include rural participants and do the interviews by telephone was made to provide greater breadth to the experiences as some common themes arose that were particular to living in urban centres. Strategically, recruiting rural carers also provided an opportunity for the less visible populations to be represented.

The breadth of the data obtained from the participants encompassed data that surpassed the boundary of sleep related activity. The data included experiences of caregivers surrounding the transitioning of the care recipient into an RAC facility and after the death of that person. This data, therefore, was ideal for providing a platform for investigating these transitional points, therefore, the interview transcripts and audio files were made available for the current study. The original participants were informed and given the option to withdraw from this study (See Appendix E**).** None of the original twenty participants took this option. Two of the original set of interviews, however, were not included because of the nature of the relationship between the carer and the care recipient. For those two participants, the nature of their relationships was not that of a long-term co-resident relationship. This criteria was decided upon as the focus for this study was on experiences of caring for a long-term partner or companion living in the same residence. In this way, eighteen participants were included in this study.

Participants

All participants had been in a long-term co-residency relationship with the care recipient. All participants had experienced transitioning the care recipient into a RAC facility with eight of the participants also experiencing the death of the care recipient while in the RAC facility. All eighteen of the participants identified as European/Pākehā descent. There were fourteen women and six men and their ages ranged from 64 to 87 years with the median age being 75.5 years. Participants who were interviewed face-to-face in their homes lived in urban areas in the lower North Island and participants who were telephoned lived in rural areas in the lower North Island and throughout the South Island. Seventeen participants were in a partnership relationship, and one person's relationship status with the care recipient was not stated but they had been long time co-resident companions. All participants names were

changed throughout this thesis to ensure anonymity. For further details of the sample see Table 1 below.

Table 1.

Participant characteristics

Caregiver	Care Recipient	Care Recipient Age	Relationship	Type of Dementia	Cared For By Caregiver (yrs)	In RAC (mths)
Sonia	Martin	68	Married	Mixed	6	11
Sally	Roy	77	Married	Unknown	4	3
Sue	Brent	79	Married	Probably AD	4	Unknown
Nathalie	William	64	Married	Vascular	3.5	16
Sarah	George	82	Married	Vascular	3.5	12
Pamela	Tony	75	Partner	Vascular	5	8
Ruby	Adam	86	Partner	Unknown	Unknown	24
Olivia	Holly	73	Co-Resident	AD	3.5	13
Joe	Fiona	71	Married	FTD	4.5	15
Steven	Karen	83	Married	AD	3	10.5
John	Linda	83	Married	Vascular	3.7	5
Jacob	Ivy	87	Married	Unknown	3	11
Daniel	Lucy	73	Married	AD	5	7

Note. AD = Alzheimers Disease; FTD = Frontotemporal Dementia

Data Analysis

The purpose of this study was to provide an in-depth and detailed account that captures meaning and provides insight into a caregiver's world before and after the decision was made to transition the care recipient into a RAC facility. This process involved listening to audio files of the participants' interviews to ensure that the original transcripts were accurate, and reading, coding, and analysing transcripts.

This study followed the Murray (2000) guideline for formulation of an intentional narrative analysis as outlined in the methodology section. As each interview was checked for accurate transcription, I began to engage with the data, noting the overall structure, function, and content of the stories. Immersion with the data was developed further with a detailed reading and re-reading of the transcripts that defined, refined and elaborated on each previous reading. Content from each individual transcript was then coded using NVivo software (Massey University, 2019). Throughout the coding process narratives where also identified and coded. When coding was finished an examination of the codes was completed to define common narratives within the set of transcripts that were relevant to my research. Once identified, the common narratives were further examined to identify the structure and function of those narratives. This was achieved by asking myself questions as I examined the narratives such as the following: What position is the participant wanting portrayed? What is the meaning the participant wants acknowledged? Why is this participant's narrative described in this particular sequence? Why is this participant's experience the same or different? Furthermore, during this time the common narratives were explored as to the personal, interpersonal, positional, and ideological levels of narrative. This was managed by asking the following questions: What socially motivates the telling of this narrative? What is the participant's voice and what is mine? What moral, social or identity stance is this person taking?

As the common narratives were re-fined in this way, I began to write the analysis section. This was an inductive process driven by data rather than from a preconceived framework. Extracts were chosen after careful deliberation of how they interacted with the narrative being presented. My interpretation after each extract was analytically examined and then edited to provide clarity on the structure, content, and function of each narrative. The link between narratives and the wider social context was also documented as narratives are not formed in isolation from the social world within which participants live (Wong & Breheny, 2018). Additionally, my input is also visible through the use of ellipses "(…)" to indicate where speech was removed because it was irrelevant to the experience being explored and square brackets "[ ]" were inserted where further context or clarification was needed. By this approach, narratives of the participants' experiences of the decision-making process and after that process emerged authentically. It also allowed for a socially driven analysis rather than a categorisation of descriptions. A socially driven approach aligns with social constructionism and narrative methodologies (Silver, 2013; Wong & Breheny, 2018).

Chapter 6: Findings

The following narratives have been considered as a set analytically that characterised the journey for caregivers prior to and after the decision-making process of transitioning the care recipient into a RAC facility. Many narratives are interwoven, which aligned with both the complex interlocking nature of the symptomatic trajectory of dementia and peoples multifaceted structuring of narrative through conversation. Further, many of the following narratives have emerged because of a negative shared social context of RAC facilities. The participants have described in their own words what brought them to the place of making the decision to transition the care recipient into a RAC facility even when the decision that was made was not theirs alone. The story that participants have detailed also highlighted their struggle with and resistance towards making the decision to transition the care recipient because they were embattled by the social message that RAC facilities are not ideal. Furthermore, participants will then privilege the listener with their narratives of how they felt about the decision and how they re-structured their lives to make them more manageable after the decision.

This chapter, therefore, explores five narratives. The first three narratives occur prior to transitioning the care recipient into a RAC facility. ‘This is why I had to’ examines the caregivers’ decision-making processes through the lens of the trajectory of dementia symptoms. ‘They said I need to’ is also a consequence of those symptoms, which examines how caregivers framed the decision-making experience when a health provider recommended RAC. The third narrative ‘It was a last resort’ examines how a shared social understanding of RAC facilities as an undesirable place only used when no other options are available influenced the decision-making process. Therefore, this section explores how this understanding created a story of ‘resistance’ towards transitioning the care recipient into a RAC facility. The next two narratives both occur after the decision for RAC transition has

occurred. The fourth narrative ‘I made the right decision’ characterised the narratives that caregivers expressed after the care recipient was transitioned into a RAC facility and how they maintained that stance and the fifth narrative ‘This is how I am adjusting’ described what caregivers did that re-structured their lives to fit their new circumstances.

This is why I had to

‘This is why I had to’ explored the narratives that influenced the participants’ decision-making process for transitioning the care recipient into a RAC facility. The majority of participants’ had sequenced these narratives by describing a framework of factors that came together as a set. Personal descriptions of the factors that made up the set sat at the ‘personal story’ level of narrative; therefore, participants’ sequencing of the influencing factors varied. The variation occurred because participants’ stories provided the sequence that made for them the most sense out of their experience. It was, however, participants perception of their ability to continue within the environment created by the ‘set of factors’ that was characterised as the most important reason for why the decision for RAC was made. This narrative started by exploring the most commonly described three factors that contributed to the set.

Progression of Symptom Severity, Challenging Behaviours, and Safety. For most participants the framework of factors that underpinned the final decision for transitioning the care recipient into a RAC facility included progression in severity of symptoms, management of challenging behaviours and safety. The following excerpt was chosen because it provided a narration of these three factors in sequence. The except is from Joe who cared for his wife Fiona for 4.5 years in their home before Fiona transitioned into a RAC facility. Fiona had been diagnosed with frontotemporal dementia. Joe’s excerpt began by outlining how Fiona’s symptoms became progressively more severe.

Int: So, would she be getting up in the night, as well, or she was just kind of doing stuff in her - it sounds like she was doing stuff in her sleep.

Joe: In the initial stage, it was just the movement in the bed. In the latter stages, she would get up and walk around the house. She'd know she was walking around the house, but she didn't know why she was getting up. That wasn't her pattern.

She never did that. Okay, once she went to bed, that was it for her. But yeah, for instance, so when we walked around the house - I bought her a keyboard for a birthday. She could play the piano before she got sick so I bought her a keyboard and she would get up in the middle of the night, and she loved the keyboard. She'd get up in the middle of the night and start banging away on the keyboard and initially there would be music but as she degenerated the music just turned into scales from low to very loud.

Joe's description detailed the progression in the severity of symptoms experienced by Fiona. Initially, Joe has outlined that Fiona's initial symptoms did not overly affect him as she kept to her bed. As Fiona's symptoms progressed in severity; however, Joe had to be up in the middle of the night, which affected Joe significantly because it created disruption to Joe's previously customised nightly routine. Furthermore, Joe's description highlighted that he had initially found a solution that kept Fiona busy while she was awake during the night. This solution because of the change in the severity of symptoms, however, went from being helpful to a factor that added to the disruption for Joe.

Continuing on in the interview Joe describes another of Fiona's symptoms that has not only progressed in severity but has also become challenging for him to manage. While

Joe described the challenging behaviour he also located a need to consider Fiona's safety connected to the challenging behaviour.

Int: (…) was there a leading up to, sort of, her moving out of living with you, was there a particular event or I mean obviously you're saying sleep was pretty bad, but you know was …

Joe: She walked all the time (…) she'd do a circuit around here. I mean, we're talking half past six in the morning. As soon as she'd woken and she was out, and then she'd time everything by a clock.

I could hide clocks and try to get her watch off her and things like that, because everything had to be done at a half hour or on the hour or something like that. So, 10 o'clock came, oh it's walking time. At 10 o'clock walk was a village walk or 10 o'clock, half past 10 walk, was a walk around the streets walk and when she walked out on the streets she was unaware. As she - common sense things, I don't need to tell you, that they don't look when they cross the road. They are so naïve with people who talk to them out there, and this is a nice environment in here, but it's an interesting neighbourhood in sections around here, and it's not the sort of place there that you'd put a woman and a man perhaps out there, and say, "Well, yeah, you're completely safe".

Int: Oh, yes, when she was walking, yeah.

Joe: Yeah, and that whole trusting nature, you know, and she walks up to people, basically gets right in their face and waves at them and says, "Hello" as if that person is her next best friend.

Joe provides an in-depth description of Fiona's walking behaviour and the measures he implemented such as hiding clocks in the house to control that behaviour. Firstly, by describing the challenging behaviour in detail, Joe hoped the listener understood how

disruptive and difficult the behaviour was for him to manage. Secondly, by describing the measurements he took to control the behaviour, Joe hoped the listener understood that he did everything he could to control the behaviour but was unable to. In this way, Joe has begun to build a framework to account for the requirement of RAC. When Joe's story changes to a description of considering the dangers to Fiona's personal safety while walking, Joe is positioning himself as Fiona's protector. This means that he considers himself responsible for Fiona's safety even when she is not with him. Later in the interview, Joe confirms his position of protector when he makes it explicit that his concern for Fiona's personal safety was not just a transient consideration but that he took action to minimise harm by having a safety response plan in place when he could not be with her.

Int: Yeah, so if she hadn't come back.

Joe: If she didn't walk the four loops or if she disappeared after one, I'd get a phone call.

Int: That's good.

Joe: There were people who I met, who lived in a street out of the village - I'd know them from many years ago, but I didn't know they were there, until I re-met them. They spotted her for me when she headed out the main gates and headed out towards X Highway and they kept a good watch on her too. So, it wasn't just, "Oh there she goes again". They just - they watched her.

Joe would continue on and describe that the above safety plan became obsolete when Fiona's walking went beyond the boundaries of where she could be watched. At this point in the interview, Joe has provided a complete description of escalating symptoms, challenging behaviours, and safety management responses that did not work. By doing this, Joe has not only accounted for his decision but has provided a complete framework of information to the listener, which outlined the necessity for RAC. This is why Joe's next statement shifted from

talking about Fiona's symptoms and his response to those symptoms when he stated; "another part of the package of, I can't do this anymore". In this statement, Joe has tied together the events, behaviours and safety management measures that he had previously described to the listener.

This means that Joe has evaluated all of those factors as a set rather than individually focusing on a specific factor. Furthermore, Joe has expressed that his evaluation of the set of factors has meant that he can no longer continue to provide care in the way he had previously. Joe's story, however, does not end at this point. Joe has not just taken into account the above factors and then made the decision for Fiona to live in a RAC facility as the next excerpt from his interview highlighted:

Int: Oh yes when she was walking (…)

Joe: "So, all those little bits and pieces like that, I was putting up with but I couldn't - showering and personal care became issues. Feeding, she'd eat at three o'clock and then have an evening - her evening meal at three o'clock in the afternoon. Initially I was making the meals, but she didn't want the meals. She only wanted microwaved vegetables. That's all she ate, apart from cereal in the morning, and she - she cooked a handful of microwave vegetables one day and she could manage the microwave okay. Three minutes for a bowl of vegetables so I let her do it but that stopped the day that she cooked them for 37 minutes and I couldn't figure out what the smell was in here. It was black plastic, blacker what would've been vegetables and that was the end of that. So, the whole compendium of issues over a 24 over the whole 24 hours spectrum that became - that were manageable, that became less and less manageable and I kept saying to my friend, "How do I know when it's time?" and he said, "Oh you'll know" and I actually - it was just a rush of events."

When Joe detailed the above events he again highlighted that there was an accumulation of factors that came together. At this point, however, Joe had already indicated that he had evaluated the set of factors and decided he could not continue in the caregiving role as he had previously. What Joe has indicated in this part of his story is that although he knew he could not continue as he had previously he still had not made the decision of RAC for Fiona. Joe made the decision for RAC when the set of events went from being manageable to being unmanageable. This means that Joe evaluated not just the set of factors but his ability for the management of those factors. When Joe decided that the resources he had to manage the situation where no longer sufficient to provide adequate provision of care, Joe made the decision for RAC for Fiona. Joe, however, has also made it clear that the turning point for him in the decision-making process was when the two elements (set of factors/management of those factors) came together in a rush over a short time span. This description of the events highlights the chaos of the situation that Joe was trying to manage.

In this narration 'this is why I had to' Joe has provided a clearly articulated series of events that contributed to his decision for Fiona to live in a RAC facility. The way Joe structured his story made it appear that those events unfolded in a straightforward linear manner. This was partly because the interview process itself was fundamental to the way Joe sequenced those events and partly because Joe ordered the events in a way that made the most sense to Joe of his experiences. Furthermore, Joe also ordered the events to best convey meanings that he wanted the listener to understand. The events themselves as can be seen by Joe's final comments, however, are anything but straightforward or linear in nature.

In common with Joe, many participants told stories that demonstrated the connection between the most commonly detailed factors; progression in severity of symptoms, management of challenging behaviours, and safety. Likewise, those same participants made

the connection between self-assessment of the ability to manage and transitioning the care recipient into a RAC facility.

This next excerpt was chosen, however, because it provided an example of how sequencing of factors varied based on the participant's unique experience of the events. The excerpt is from Sue who is married to Brent. Sue was Brent's caregiver for 4 years until Brent transitioned into a RAC facility. Sue, like Joe, began by telling a story of progression in severity of symptoms. Sue's excerpt started with her talking about the move to sleeping in separate beds because Sue was kept awake at night because of Brent's 'twitching' in his sleep. The interviewer followed up on this shift in their relationship by asking Sue about how this provided a better opportunity for sleep. This focus aligned with the original study on dementia and sleep.

Int: So you provided yourself a good opportunity for getting sleep.

Sue: (…) he'd be in the bed with me and then we'd get up. (…). He was still physically very fit for his age and he was still gardening for people because he liked to (…). He was already 84/85 and he would come home from his gardening jobs and quite often someone would ring up and say "oh Brent's left his secateurs behind" or "Brent's left his clippers" and we didn't think much of that (…). You just think oh a bit of forgetfulness like we all are from time to time. Then as a bit of more time went on I noticed, I don't drive and when I was sitting in the car with him I noticed he was getting a bit indecisive "what do I do now?" because I think the rules had changed about going round corners and things and he was asking me and I thought well that's not very good if you're needing to ask me and I noticed a difference, and apart from that I started feeling tense in the car with him because I could tell he was a bit indecisive.

The story that Sue told began with what appeared to be a slight nuisance, Brent's forgetfulness. This sets the scene for escalation to a level of indecision that begins to border on dangerous when it interferes with Brent's driving. Sue recognised the level of risk and like Joe positioned herself as Brent's protector. Sue also like Joe, therefore, proactively took steps to mitigate harm when she described the following action that she took: "when he came to the age of 86 and had to do a proper test I said to the doctor again about my concerns and they decided then that he shouldn't have his licence because of his test."

While staying within the context of a progression of symptom severity, Sue described other challenging behaviours and her management of them.

Sue: (…) there were little incidents happening from then on in the night, one day he came into my room saying "where's James?" and James was his brother, when he was in Holland they had a big family and they were quite poor and they had a very small house (…), and he slept with his brother James (…). And he said, "where's James?" he came in about 2 o'clock in the morning (…) and he said, "Yeah James he should be in bed with me and I've been out in the lounge and he's not there, where is he?" And I said, "Oh I don't know" I had to think quick, I didn't know what to say (…). From then on there were little incidents of him coming into the room or another day I'd been out doing the gardening – he used to be a great gardener but he eventually lost interest in the garden (…) and I was doing a bit of gardening and he, I came inside at afternoon tea time and he said to me "where's Dad?" His dad died years and years ago, I said "oh I don't know, why?" And he said "oh he was out in the garden with you before" and he said "I can't see him anymore." And I said "oh he must have gone home" and so funny little incidents like that but increasingly he got, over the last four years, he got faecal incontinence.

Sue's story started with a description of symptomatic behaviour, which is to a small extent challenging for her as Sue indicated it happened at times in the middle of the night. Furthermore, at those times, Sue described how she had to think quickly to formulate answers that made the situation manageable. At the end of Sue's narration, however, she provided a description of a major challenging behaviour, faecal incontinence, which the interviewer picked up on.

Int: Oh right that's challenging.

Sue: It was very challenging and also coming into the bedroom at half past one and wanting to get dressed and I'd say "no go back to bed, it's not time to get up yet" about half past two or whatever he would be back again, sometimes three, four times wanting to get dressed, which was – didn't help with my sleep but whether I would have slept anyhow, but then the faecal incontinence. I was determined to keep looking after him and that was what I wanted to do, but he was – his bowels seemed to be very loose and they were – I'd have to change the whole bed (…).

When Sue answered this question she agreed with the interviewer that faecal incontinence was challenging. Sue then shifted away from that topic and detailed other symptoms that were also problematic, only to return to discussing faecal incontinence. In this way, Sue has chosen to highlight to the interviewer that although faecal incontinence was probably her most challenging symptom for management, other symptoms were also involved in her management of care. This means that Sue is wanting the listener to know that it was not just one factor that she focused on as being the explanation as to why the caregiving role became unmanageable for her.

In spite of the progression in severity of symptoms, challenging behaviours and required safety measurements that Sue has previously described, Sue would still locate her ideal as continuing to be able to manage these requirements and keep Brent at home. Sue's next comments, however, have shown that her ideal was not achievable because management of the factors in a way that changed the situation was not possible. With no change in the situation Sue eventually commented in this interview "I did the best I could, I couldn't do it any longer". Sue had come to a point where she has realised that the situation has moved beyond the resources she had to manage. At this stage she transitions Brent into a RAC facility.

Joe's story like Sue's sequenced progression of symptom severity, challenging behaviours and safety management. The difference between the two stories, however, is when Sue and Joe made sense out of their individual experiences they sequenced the factors that contributed to RAC in different ways. This was because the symptom trajectory for each care recipient was different. For instance, because of Brent's symptoms, Sue described the need for safety management before she described Brent's challenging behaviours whereas because of Fiona's symptoms, Joe described Fiona's challenging behaviours before safety management. In this way, Joe and Sue present their experiences in a way that makes the most sense for them, which allowed for nuances of the experience to emerge. Nonetheless, both Joe and Sue regardless of how they sequenced the influencing factors, they evaluated those factors as a set and then decided if they could continue to manage. The result was that both Joe and Sue came to the same conclusion that when they felt they could no longer manage the set of factors as a whole then transitioning the care recipient into a RAC facility was necessary.

Additionally, through explicitly highlighting the challenges they were managing on a daily basis it emphasised to the listener how difficult their situation was. When Joe and Sue detailed the difficulties they were experiencing they accounted for their decision and hoped that this knowledge would ultimately provide the listener with a framework of understanding as to why a transition of the care recipient to RAC was absolutely necessary.

Caregivers' Physical Health. For some of the participants there was another factor that contributed significantly to the 'set of factors' that made remaining as a caregiver no-longer an option. This section highlighted that difficulties commonly arose for caregivers in relation to their own physical health needs. The physical health of the caregiver, therefore, was commonly linked to participants needing to transition the care recipient into a RAC facility. The first excerpt is from Olivia. Olivia was Holly's co-resident companion for twenty-five years, and in last three and a half years of residing together Olivia was also Holly's caregiver.

Int: How long ago did she go into care?

Olivia: She's been in a year in June. (…). She went in because I had to have a new joint put in my middle right finger because it had seized up with arthritis, and the surgeon said I couldn't mind her for six weeks, so I'd put her in for two weeks at respite care. I had to apply for an extension and they said, oh no, think they should keep her because she loves it there. I had to weigh that up, mind you. I couldn't really go on like that because I was washing three times a day because of the incontinence.

Olivia's story has described her experience of difficulty with her physical health as the catalyst for assessing her situation. From this assessment, Olivia decided that not only was RAC a necessary option because of her physical health limitations but also the right option because of Holly's acceptance of RAC. When Olivia told her story; however, she emphasised

that she took time to make the decision. At the same time, Olivia also supplied evidence that her decision to transition Fiona into a RAC facility was necessary. In this way, Olivia has accepted responsibility for the decision but also justified why she had to make that decision. Another excerpt that further demonstrated the way that the physical health of the caregiver can affect the decision-making process comes from Ruby, who was a caregiver for her partner Adam. The excerpt started after Ruby had been talking about being taken to hospital after a fall. The fall resulted in Ruby sustaining a broken pelvis. Ella [Ruby's daughter] took her mother's place temporarily to care for Adam but soon realised that he needed more care than she could provide; therefore, she had Adam admitted into respite care.

Int: So is this your daughter [Ella]?

Ruby: Yes. [Adam was taken] to respite care while I was in the hospital and I was in hospital with this broken pelvis (…). I was in there for quite a long time because I developed a bad bedsore which developed into an ulcer, which when I came out I was in a wheelchair because I was supposed to keep my leg up. At that time Adam had been reassessed here [Adam was in respite care in RAC facility] and popped upstairs into the dementia unit. (…). I was trying to get around with a very bad foot and when I got back, as I said, when I got back I thought, oh well perhaps he'll come back out again. So I went up a couple of times to see him in the wheelchair and it turned out that no, he wouldn't be able to come back with me because I wasn't on my feet and not able to look after him properly.

Ruby has detailed that because of complications after her injury she had no choice but to leave Adam in the RAC facility because she was deemed physically unfit to remain in the caregiving role. When Ruby highlighted this as part of the description of events, Ruby has

situated her decision as not being of her own making. Ruby unlike Olivia, did not accept responsibility for the decision although similarly to Olivia, she provided this information as justification to the listener for why the decision was made. In this way, similar to Joe and Sue, Olivia and Ruby hoped that this knowledge would ultimately provide the listener with an understanding of why RAC was absolutely necessary.

They Said I Need To

'They said I need to' examined the way participants framed the decision-making process when a health professional's assessment suggested or urgently recommended the care recipient be transitioned into a RAC facility. This section, therefore, will explore the narratives that surround the caregiver when the sole responsibility for the decision-making process is relinquished. Commonly, most participants in this study viewed the decision-making process as a positive experience when this occurred.

This first excerpt has been chosen as it is a clear example of how the recommendation from a health professional was instrumental in making the decision for transitioning the care recipient into a RAC facility. The excerpt is from Steven who was a caregiver for his wife Karen for three years in their home. Steven had been managing a set of symptoms that Karen experienced as part of her dementia journey. Those symptoms included agitation, confusion, delusions, anxiety and wandering. Steven's excerpt started after describing those symptoms, his management of them and the affect they had on him. At this point in the interview the interviewer is, therefore, asking about support systems Steven had in place to help him manage.

Int: (…) like you say you had that support in the morning and evenings when she had had a fall, but other than that you didn't have any respite?

Steven: No.

Int: Or support in the day?

Steven: No. Dr [name], do you know Dr?

Int: No.

Steven: She is extremely good, marvellous. She assessed Karen originally here. (…) and they chatted and it flowed beautifully, and I thought, gosh you know, how's she going to pick that Karen's got, and afterwards Karen went out with one of the nurses that also came, they wanted her out, and she said straightaway, yes she has…

Int: Something going on?

Steven: Yes, she knew. Well she was trained to see through it all. So then she was assessed and then it just got worse and worse month by month, and in the end they said she could go into residential aged care to give me a week's respite. Then when she got in there and then they said, there was no point in bringing (…) and her own doctor also looked at her and did it again, and said there's no point in her coming home.

Int: So right, so wasn't really your – was it, did you feel it was out of your hands a little bit or?

Steven: Oh yes. But I knew that it was correct.

Steven after this again reiterated that it was the correct decision when he expressed that it was the best place for Karen as he could not have continued on with the way things were. Steven's story located Karen as having had an assessment by a doctor early on in her dementia journey. Steven indicated that he believed the doctor was well-trained because they recognised Karen's dementia although Steven thought it was difficult to diagnose from the way Karen had acted. Once Steven decided the doctor was well-trained and competent he then perceived the doctor as being an authoritative person whose professional judgement

could be trusted. This made it easier for Steven to accept the doctor's recommendation when later they advised Steven to leave Karen in the RAC facility. When Steven confirmed he accepted the doctor's recommendation, he highlighted that he relinquished responsibility for the decision. The responsibility shift for the decision was expressed as positive by Steven. This is because when Steven did not have to make the decision he was not influenced by any of the negative consequences connected to making that decision such as guilt. This allowed Steven to re-evaluate his situation and describe how he was not managing anyway.

The experience of moving into a RAC facility via a health professional's recommendation was a common representation of the interviews. The next excerpt further highlighted the commonality where the decision is not made solely by the caregiver although it is still perceived as a positive experience. This excerpt is from Sarah who was a caregiver for her husband George for three and a half years. Prior to this excerpt, the interviewer had enquired about the events that were the catalyst for making the decision. Sarah had not responded to that question but had explained that she had done some future care planning for George by visiting RAC facilities. The interviewer at this stage, therefore, was encouraging a further description of events that were the catalyst for making the decision for RAC.

Int: Yeah, you had to make the decision…..

Sarah: That's right, you were sort of saying what made the decision, what brought me to that point. So I knew where I would want him to go. And I knew that at home I was not, I was, you know I used to say oh it's easy, it's relatively easy. I knew it wasn't really. And that I was beginning to go downhill. And when I said to my doctor (…) oh it must have been when [George] wasn't there because we share a doctor. He was very good.

Int: Great.

Sarah: I said that when you think George is ready to go into care. I'm ready for that to happen. And he said right, he said he can go now. Do it now.

Int: Wow.

Sarah: I asked him why afterwards [why he made the decision] and he said because I could see you both going downhill and I didn't want that to happen. I said I was ready, and Doctor said it's time. Cos it's really hard to say. You're just too, oh, it's the same thing really I suppose. But it seemed, seemed easier being told yes.

Through this description, Sarah has located the catalyst for RAC as being the visit to the doctor's office although she had already decided that RAC was necessary because prior to the visit she had picked an RAC facility that would be suitable for George. This would suggest that the catalyst for RAC happened long before the doctor's visit and his subsequent recommendation but by locating the catalyst as the doctor's visit, Sarah situates the responsibility for the decision as not her own. Although retrospectively Sarah comments that she recognised that her being ready was the same thing as the doctor saying it was time. Through this comment, Sarah has let the listener know that she was competent in her role as a caregiver to assess the situation but that she could not proceed with what she knew was required until she received the doctor's recommendation to 'do it now'. In Sarah's story, the doctor's recommendation provided Sarah with the motivation to go ahead with the decision. This was because Sarah like Steven found the process easier when she relinquished responsibility for the decision to the doctor.

Importantly, however, Sarah mentions that she and George had a prior relationship with this doctor and from those transactions with him Sarah believed him to be a very good doctor. This meant that Sarah trusted this doctor had the necessary competency and skills to

make accurate recommendations with her and George's care. Because of this trust, Sarah was able to relinquish responsibility for the decision to this doctor.

There is, however, not always ample time to consider a recommendation. Sometimes transition to RAC is advised as requiring urgent attention as the following excerpt highlighted. This excerpt is from Jacob who was a caregiver for his wife Ivy for three years in their rural home. Ivy had fallen at home and her risk of falling again was high and this is the reason transition to a RAC facility was urgently advised as necessary by the doctor. The excerpt starts with the interviewer enquiring how Jacob feels about the decision-making process.

Int: Yeah, and because it sounds like the decision to move her into RAC, it sounds like it was taken out of your hands a bit (…).

Jacob: Well, we looked when the doctor said she's got to go in care. We looked at [RAC facility], which is half an hour, at least half an hour from here, no, probably more. [RAC facility], which I would have preferred because that's a good place and I know they really look after people, there was no room there, we had to wait for two months, and same in [RAC facility], we had to wait, there was no space at that time. Or go to [RAC facility], which is the closest but was not our choice but well at that stage she needed care so there was nowhere else to go.

Previously, in the interview Jacob had accepted that what the doctor had advised was necessary because he did not want Ivy to be injured again. Jacob's narration, however, positions the decision for transitioning Ivy to a RAC facility as being rushed because the doctor suggested that the transition needed to be urgent. Jacob then links the narration of being 'rushed' as the reason why he transitions Ivy into a RAC facility that he describes as less than ideal. Jacob was the only participant who described his choice of RAC facility as

‘rushed’ and he was also the only participant who did not comment positively about the decision-making process with a health professional.

Steven and Sarah’s stories are similar as they are wanting the listener to understand that recommendations that were given to them by a health professional were made in a competent capacity. In this way, Steven and Sarah are endorsing to the listener that the medical professionals were a positive and valuable resource that was instrumental to their decision-making process. This has come about because both Steven and Sarah viewed the health professional who made the recommendation for RAC as competent and well-trained to make accurate recommendations. Steven and Sarah, however, did not come to this conclusion because health professionals are socially understood to hold authority in health matters. They came to this conclusion through observation of situations that provided proof that the health professional was competent. This was unlike Steven who had the reverse experience. Steven wanted the listener to understand that health professional’s do not always provide the best support because his health professional’s advice left him feeling ‘rushed’, which did not fully support a good outcome for Ivy.

It was a last resort

‘It was a last resort’ examined the participants’ stories on the ‘ideological’ level of narrative where systems of socially shared beliefs and understandings, which underpin decision-making, are explored. This section, therefore, explored the participants’ narrative of resistance. Participants commonly told a story of resistance towards transition of the care recipient into a RAC facility even when their own well-being was affected. Furthermore, when participants storied the extent of their own exertion to keep the care recipient at home they justified to the listener that there was an absolute need to transition the care recipient into a RAC facility, before the transition was decided on. This highlighted the social context of RAC facilities as a last resort option.

The first excerpt was chosen because it provided a clear example of how the participant's well-being was ignored in favour of keeping the care recipient at home. The excerpt is from Pamela who was a caregiver for Tony. Pamela cared for Tony in their home for five years before he transitioned into a RAC facility, which was eight months prior to her interview for the sleep study. Pamela had resisted transitioning Tony into a RAC facility until Tony was admitted to hospital with a health crisis. The hospital at that time advised Pamela to make the decision. The excerpt starts with the interviewer talking about how Pamela is still having a problem with sleeping at night after Tony has gone into care.

Int: So it's different now. I suppose you were, having to sort of like you say, physically support him going to the toilet and getting him back to bed, but now it's just, just remaining [not sleeping].

Pamela: Well when he went into, I didn't realise how tired I was. I was, you know, I guess I was like an autometer really. I was just working, looking after his needs and thought I was caring about myself as well. There were days when I was very shaky.

Pamela: I had very little respite care because he wouldn't want to go (…) he would get aggressive and it wasn't easy. I got him into one rest home. They rang me at one o'clock in the morning and said can you come up and I said "well, I wouldn't have put him there and for two nights, because I need the sleep, if I had thought I was going to come up but anyway I had to go up." So that was a whole night's sleep I didn't have there from one o'clock through till five I think I left, which is unfortunate but there were times and I mean, and you know when you're crashing, because your legs get very wobbly and I was close to it.

The interviewer has queried Pamela's lack of being able to sleep (aligned with the original sleep study) since Tony transitioned into care but Pamela's response does not relate to the question asked. Pamela choose instead to story how tired she was when Tony went into care. Pamela would again and again throughout the interview detail her exhaustion. There is a reason that Pamela repeatedly described this. Pamela wants the listener to gain an understanding that she resisted transitioning Tony into a RAC facility until it was absolutely necessary. Pamela justified the 'absolutely necessary' to the listener through the frequent narration of exhaustion. Furthermore, the extent of physical exertion that Pamela tolerated rather than transitioning Tony into RAC emphasised her belief that RAC facilities are not an ideal living situation and should only be utilised when no other option is available. Resistance to making the decision for RAC and justification for the transition to RAC was a common narrative among caregivers. To further demonstrate the commonality of this narrative the next excerpt has been chosen. The difference between this excerpt and Pamela's excerpt is that it highlighted that caregiver well-being was affected not just on a physical level.

The next excerpt is from Grace. Grace who was a caregiver for her partner Edward for three and a half years before Edward transitioned into a RAC facility. The excerpt started after Grace had outlined her management of Edward's symptom trajectory, which included not sleeping, confusion, repetitive questioning, and incontinence. After outlining her experiences, Grace told the interviewer that she needed temporary respite care for Edward because she became desperate, but was unable to get it because of Edward's stage 3 status [secure unit necessary]. The excerpt, therefore, started with the interviewer enquiring about the desperation.

Int: So do you think, when you say you were sort of at the end of your tether, do you mean like, just overwhelming sort of dealing?

Grace: Yeah I just knew. I'd had a breakdown once before and I knew I was heading there. And the reaction when you're not coping is not good for them, because you're not, you know, you're, you're losing your cool.

Grace's story highlighted that although she knew her mental and emotional status was on the verge of becoming a mental health crisis, she still chose not to transition Edward into an RAC facility. At this stage, Grace was still hoping that she could manage the situation with the help of temporary respite care. Grace also mentions that when a permanent bed became available in a RAC facility, her family told her it was time to do it. It was, therefore, only after temporary respite care was not an option and with the reassurance from her family that Grace made the decision that Edward needed to transition to a RAC facility on a permanent basis.

Grace like Pamela told a story of resisting RAC, even when her own well-being was adversely affected. In this way, both women have demonstrated to the listener a commitment to keeping the care recipient at home whatever the cost to their own well-being. By pointing out what that cost was, however, they have also justified that RAC was absolutely necessary before the decision was made. Grace would also take this a step further when she mentioned that her family had told her to make the decision. This added to Grace's accounting for the decision. Grace and Pamela's stories represented a common pattern among participants; resistance before the decision and justification after the decision. These stories are founded on an implicit belief that underpins the resistance and justification. That belief was that RAC facilities provide a less than ideal living option that a person should only enter into as a last resort.

I Made the Right Decision

Many of the participants in this study commonly described how difficult it was to make the decision to transition the care recipient into an RAC facility. After the decision;

however, a new narrative developed. A narrative that told a story of the decision being the right one. ‘I made the right decision’ was arrived at by participants when they retrospectively reviewed the decision.

For some participants the narrative of the ‘right’ decision was settled on when they viewed the care recipient in their new surroundings. For others, it was connected to keeping diaries that reminded them of the necessity for making the decision. The first excerpt was chosen as it was a well-articulated example of how viewing the care recipient retrospectively in a RAC facility provided evidence to the caregiver that the decision they had made was the right one. Nathalie was a caregiver for her husband William. Nathalie cared for William at home for three and a half years before he transitioned into a RAC facility. William had been in a RAC facility for 16 months at the time Nathalie was interviewed.

As William had been in care for some time it allowed a space whereupon Nathalie reflected on how she would have managed if William had stayed at home. The decision to transition William into care was recommended by a hospital gerontologist**.** The excerpt, therefore, started with the interviewer enquiring about the fact that the decision had not just been Nathalie’s.

Int: Right. So he's kind of was, wasn’t a decision you sort of?

Nathalie: It wasn’t a position where I had to think look, is, you know. He's not bad enough, but maybe he needs to go in or whatever. (…) God I'm so glad I did because like in the home, he was just even worse. All they could have in his bedroom was a bed. Because he urinated in drawers, up the wall, and over the chairs.

Int: Yeah so I guess if you brought him home.

Nathalie: It would have been terrible. Yeah there would have been dire consequences I think really.

Nathalie's description started by her indicating her relief that firstly the decision had not been solely her responsibility and secondly that the decision had been made. Nathalie then shifted in her description to discussing her observation of William in RAC. She does this to explain why she was glad the decision was made. Nathalie explained that through her observation of William in RAC she noticed a deterioration in Williams condition. Nathalie's realisation of William's progression in symptom severity in RAC could have been a reason to remove him from the RAC facility if she had chosen to view his care from a negative standpoint. Nathalie, however, has chosen to position William's condition as the reason that his symptoms had progressed and not because of the care he had received. This allowed Nathalie to situate the RAC facility as the appropriate place for William because of his deteriorating health status. This represents a challenging health status that Nathalie realised one person could not manage in a home environment. Making these determinations led Nathalie to situate the decision of RAC for William as the right one.

To further cement her decision as the right one, Nathalie would also reflect back on Williams life and what he wanted out of life and connect that to his life in the RAC facility:

> He's got all these people caring for him 24 hours a day. That's all that he ever wanted (…) cos his first marriage, was quite difficult (…). All he wanted to be was just be looked after and nurtured and be kind. You know, somebody being kind to him really and that's what he's got now.

In this way, Nathalie has chosen this memory as an instrument that strengthens the belief that she has made the right decision. It would appear, however, that later when Nathalie comments that she believed William's new environment was maybe not an ideal match to what he had wished for: "You see when you ask for things, you've got to ask for specifics don't you? (…) Otherwise you might not get it [how you want it]" that this contradicts her reasoning. Nathalie's statement, however, is indicating that William's ideal for nurturing

most likely did not involve care inside an RAC facility. Nathalie believed, however, when she made this statement that the care William received from the RAC facility still fulfilled William's wish. This is because the care inside the RAC facility provided round the clock nurturing delivered in a kindly manner. In this way, Nathalie presented this memory as a reason that her decision was the right decision. Nathalie, therefore, would use both the observation of Williams advanced symptoms and the memory that RAC was a place where the care provided would be appreciated by William, to position her decision as the right one.

The 'I made the right decision' also occurred when previously there had been resistance shown towards making the decision. The next excerpt is from Pamela whose resistance for making the decision was detailed earlier under 'it was a last resort'. The excerpt started with Pamela talking about Tony's current health issues in the RAC facility.

Pamela: So because he's now got a suprapubic catheter, he gets lots of infections and you know, this is becoming resistant to antibiotics.

Int: Oh right because he has taken…

Pamela: So yes. Now he's, he has deteriorated since he's been there and he now has to be fed. He was able to stand on his legs, but he can't any longer. He's, has a hoist to. Tragic really.

Pamela commented next that she could not have managed Tony, in the condition he was now in, at home. Pamela had struggled to make the decision to transition Tony into an RAC facility, resisting it until she could show it was absolutely necessary. Regardless of the previous resistance; however, after viewing the progression in the severity of Tony's symptoms Pamela reaches the same conclusion as Nathalie that RAC was the right decision. Similar to Nathalie, Pamela also associated the deterioration in Tony's condition as a symptom of his dementia and not because of the care he was receiving. This again allowed for acceptance that RAC was the appropriate place for Tony. Pamela and Nathalie's stories

were a common representation of the ‘I made the right decision’ narrative as the majority of participants that used this narrative had observed symptom change in the care recipient, which they deemed unmanageable in a home setting.

For some caregivers; however, even when they knew they had made the ‘right decision’, they still experienced times when they second guessed their choice. To maintain the narrative of ‘I made the right decision’ some caregivers found that retrospectively reading personal diaries was helpful. This was because the dairies provided an account of the caregivers’ daily experiences of managing their care recipients’ symptomatic behaviour prior to RAC. This first excerpt has been chosen because it provided a clear outline of how a caregiver accepted they made the right decision only to start to have doubts about the decision.

The first excerpt is from Sonia who was a caregiver for her husband Martin. Sonia cared for Martin for six years in their home before he transitioned into a RAC facility. Martin’s symptoms included wandering, incontinence, confusion, and problems with movement. The excerpt began after Sonia had been discussing the difficulty of getting Martin in and out of bed while he was at home.

Int:	Yeah, because he's sort of physically needed that assistance to get in and out of bed.
Sonia:	He physically needed that. (…), I mean now [he’s in RAC], he can't walk at all. Even though there's nothing wrong with his body.
Int:	Yep.
Sonia:	But the messages just aren’t getting through. So he needs two or three people and carers.
Int:	To help him sleep?
Sonia:	And that validates the fact that I did put him in at the right time.

Int: Yes.

Sonia: I mean he was still walking when I put him into care, but that didn't last for more than six months.

Int: Like so if you're having to manually get him into bed.

Sonia: Yeah…

Int: There's only so much that you can… you can't do that yourself.

Sonia: It's just too hard, it's just too hard. So I feel happy now. It's awful to say I feel happy but I'm happy because I made the right decision.

Sonia, similar to Nathalie and Pamela observed Martin's progression in symptom severity while he was in RAC, which provided validation for her that she could not have provided the care he now required in a home environment. Unlike Nathalie and Pamela; however, Sonia continues on and tells a story of second guessing the decision.

Sonia: And lots of people always say to me, I put him in the home, but oh I want to bring him home because he's not that bad.

Sonia's description mentions that 'other' people had been talking to her about her decision to move Martin into a RAC facility and this had created an environment that made Sonia doubt her decision. Because of this, Sonia has now positioned herself as needing reassurance that Martin 'was bad enough' to remain living in a RAC facility. Sonia locates her personal diary as the perfect place to find this reassurance as the interview continued.

Int: Yep.

Sonia: I'm fortunate because I've always kept notes. So whenever I get into a panic, thinking he's not that bad, he shouldn't be in there poor love. I can look after him, I just go through my notes and I read what it was like two years ago.

Int: Right.

Sonia: And what it was like last year and because I've got that I thought no I just can't. I can't do it.

By Sonia retrospectively looking back at what occurred for her everyday while caring for Martin she soon identified with the “I made the right decision” narrative. Another participant Sue also kept a diary. Sue was first introduced under ‘This is why I had to’, where she described her experiences of caring for her husband Brent. She provided information out of this diary to the interviewer. The following is one diary entry that Sue read: “25th Brent woke at four. Told him was not time to get up. Brent needed cleaning up Sunday. Brent needed cleaning up again before going into bed. Not nice for him or me but must be done.” Sue’s reading of diary entries that she provided to the interviewer told a story of the challenging and often difficult situations in which she managed as Martin’s caregiver. The act of reading these entries was a resource that Sue utilised whenever she second guessed her decision as they reminded her she had made the right decision. Reading the entries to the interviewer also provided an account to the listener of why the decision for RAC was the right decision.

For both Sonia and Sue, distance had reduced memories of the minutiae of the daily challenges that they both managed in their caregiving roles. The lost memories allowed both women to second guess their choice. The diaries, however, provided immediate evidence of the forgotten details, which gave access to memory of the nuances of caring. Once both Sonia and Sue are taken back in time where this lost information is recovered, they are then both able to remember their ‘truth’ of the situation. In this way, the diary exercise provided clarity that supported their narrative that the decision for transition of the care recipient into a RAC facility was the right one.

When participants in this section told stories that indicated that their decision was the right one, they are providing evidence that the decision was necessary in the first place. This means that by acknowledging the decision was necessary, the decision is again accounted for.

This is how I am adjusting

'This is how I am adjusting' characterised the narratives that caregivers form within their new circumstance of being separated from the care recipient. The re-structuring that took place during this time began for some caregivers after the decision to transition the care recipient into a RAC facility was made, while other caregivers began re-structuring only after the death of the care recipient. Under the 'This is how I am adjusting' narrative, caregivers stories divided the re-structuring process into four sub-narratives.

'Finding autonomy' incorporated returning to activities that were previously enjoyed, which had been either severely restricted or stopped while the care recipient lived at home. 'Filling the gap' explored why some caregivers took on new activities rather than return to previously enjoyed activities.

'Personal Belongings' documented the caregiving experience when personal belongings are given away after the care recipient had transitioned into a RAC facility and 'Reordering the home' discussed a solution that was implemented when a caregiver had been unable to give away the care recipients personal belongings although they wanted to change their environment.

Finding Autonomy. 'Finding Autonomy' explored continuity of life for the caregiver after the care recipient had transitioned into a RAC facility, when a return was made to previous patterns of familiar activity. The first excerpt has been chosen as it clearly articulated how and why previously enjoyed activities stopped and then re-started. This excerpt is from Daniel, who cared for his wife Lucy, who had Alzheimer's disease. Daniel cared for Lucy in their own home for five years before she transitioned into a RAC facility.

Lucy's symptoms of wandering, confusion, mixing up time, and memory loss required Daniel to be constantly present to take care of Lucy's daily needs and to minimise the risk of harm. This allowed Daniel limited time to pursue the activities he had previously enjoyed prior to being required to provide dementia-related care. The excerpt starts after Daniel has described his experiences of managing Lucy's symptom progression and severity.

Int: Been really, really big support to your wife with her dementia and obviously you know, still are (…).

Daniel: But in the evenings now I'm catching up on a lot of books I wasn't able to read cos we'd be in the lounge. I would be reading something and she repeatedly oh what's the book? Who's the author? What's it about?

Int: Yeah.

Daniel: Five minutes later same thing. You just couldn't get into it. The other thing is that Google thing. Dialling up music, you know, listening to. Whether it's German folk music or Italian, you know? A couple of hours can go just listening and watching those.

Int: Yeah and so you're enjoying. Is that something that you've sort of started doing more since, since she moved out?

Daniel: Oh yeah. The music's. The singing's been my thing. My hobby all my life.

Daniel's description told the story of having to sacrifice activities that he had previously relished as part of his daily routine because Lucy's dementia symptoms made it impossible for him to be able to relax and concentrate long enough for him to enjoy them. Once Daniel was no-longer required as Lucy's in-home caregiver he has chosen to reconnect with these activities as part of the continuity of his new life. When Daniel has chosen to return to

incorporating those activities in daily life, he has indicated that this is his ideal way to live life. This also meant that during the caregiving role where autonomy over daily activities was lost, was not Daniel's vision of an ideal life. The reversion to familiar patterns of activity was a common representation of part of the re-structuring process after separation from the care recipient. Re-structuring, however, did not always take place after the care recipient transitioned to a RAC facility. For some caregivers, they only returned to familiar patterns of activity after the death of the care recipient as the next excerpt demonstrated. This excerpt is from John who cared for his wife Linda. Linda was diagnosed with Vascular dementia. Prior to this part in the interview, John described his pre-carer self as someone who enjoyed later nights and opportunities to sleep in.

Int: (…) I guess now you've got your time to yourself because like you say, the opportunity to have a sleep in and so on was compromised when you had Linda here so….

John: That's right. I couldn't even have my one day a week where I slept in till 11 o'clock or something before getting up. Occasionally it was a wet Saturday that was marvellous. It was a lousy wet Sunday, I wouldn't go sailing and I, oh beautiful it's pouring with rain, it's rotten, we're not going to be sailing today, so I can sleep in. It's just, you need one day a week anyway just to kind of unwind, and relax.

Int: So, you've got that back again now [since Linda passed away]?

John: I've got it back again. Yeah. Well I can do it any day now.

John's description has reiterated how important sleeping in was for him. As John has described, sleeping in fulfilled a need, which helped him to relax and unwind. John's description, however, has also highlighted that sleeping in was not a possibility for him while caring for Linda but that he returned to this pattern once Linda passed away. More

importantly, like Daniel, John's description has detailed that when caring for Linda he lost autonomy over the flow of his day. Also like Daniel, when John chose to return to his previously customised routines he has indicated that this is his ideal for continuity of life. Importantly, at the time that John makes these statements, Linda has passed away. John later in the interview detailed that the 'finding autonomy' narrative only began for him after Linda's funeral. This occurred because prior to the funeral although Linda lived in a RAC facility, regularly visiting her and taking care of her daily needs made it difficult for him to maintain agency over his activities.

Both Daniel and John although at different transitional periods, have described a chosen path for re-structuring their lives. This path returns both Daniel and John back to familiar patterns of activity because they are deemed as essential for continuity of an ideal life. Furthermore, when Daniel and John made this choice they reclaimed autonomy over their day, which was not achievable prior to the cessation of their caregiving duties. For Daniel and John when old patterns that provided ideal continuity of life are resumed and subsequently, autonomy is reclaimed then life after separation from the care recipient became more manageable.

Filling the Gap. 'Filling the Gap' explored ways that caregivers filled their lives to cope with the emptiness they experienced after the care recipient had transitioned into a RAC facility. For the next excerpt we return to a couple who were first introduced under 'They said I needed to', Steven and his wife Karen. Steven's story has been chosen to represent this narrative as it specifically detailed why new activities are chosen rather than returning to old activities. As noted earlier Karen's symptoms required Steven's full-time care and attention. The excerpt comes in response to the interviewer inviting a story of the journey of dementia caregiving.

Int: Yeah you have contributed your story Steven, it's exactly what we're trying to represent is not just the journey, the journey of sleep, but also your journey as someone supporting a family member with dementia, and everybody's story is so different, and that's exactly what we're trying to capture (…).

Steven: I think that I've forced myself really to do, in some ways it's very frustrating, you think oh to hell with it, I'd rather do other things. I force myself to be busy and that's helped lots because I guess it tends to make you tired at the end of the day, or it takes my mind off things so that's why I accepted to be the president of this large Probus club.

Int: Is that since Karen moved out to [RAC]….

Steven: Yes they approached me, would I be it, so I said yes under duress and then after you know, a few hours afterwards I thought, no that was the right thing to do. Cos I've got the garden club to run, I've got this garden to run, there's so many things and I thought, oh why do I do this. I mean, I could just sit around, read a book. I've been trying to start this (…) book now for so long.

Int: It sounds like you've had a life of being quite a busy person and then supporting Karen obviously was also really a busy time, so…

Steven: Well its, I've worked out that I am doing the right thing. I keep saying this to myself, don't get frustrated, don't get uptight about all the work that you're doing, it's for the community, it's for you. It keeps you busy, it keeps your mind off things. I've decided I am going down the right track, but for a while I wondered if I was overdoing it. But I'm not.

Steven's story started off by outlining that a new opportunity has come his way that after some deliberation he accepted. He deliberated accepting this position because he was already very busy with existing activities and did not necessarily deem being so busy as an ideal lifestyle option. The requirement to 'fill the gap' by accepting this new activity is driven by his separation from Karen. This is because being busy is what Steven has chosen as a resource to minimise unwanted ruminative thinking about Karen and both their new circumstances. This means that although Steven struggled to view being so busy as ideal, he still accepted it as the right way to manage his current situation. In this way, Steven has accepted being busy as part of his new identity, an identity that he has established outside that of caregiver. When Steven established a new lifestyle and identity for himself, life post Karen living at home, became more manageable.

Steven's story of implementation of new activities was a common representation from the interviews, however, implementations of new activities was not always done because it was deemed a necessity to fill the 'gap'. Some caregivers implemented new activities because they now had the freedom to choose what activities to incorporate in their daily lives. The next excerpt is from Pamela, who was first introduced under 'It was a last resort'. The excerpt starts with the interviewer responding to Pamela's account of the time she spent visiting Tony at the RAC facility.

Int: Well and it sounds, you know, you still are, you still are doing it. You're still very much a part of his care, you know. Going in twice a day and….

Pamela: I've worked my life around, you know. I'm actually doing quite a bit myself now. I've been on to a craft class this morning. So I am getting out and doing things. Went, you know, I go to movies and plays and. All sorts of things. Yoga, that I couldn't do before I can do it now so.

The interviewer's question invited Pamela to expand on her description of visiting Tony and her current status of caring for him. Pamela, however, took this opportunity to shift away from that story. Pamela chose instead a description that highlighted that she had established a life outside of the caregiving role. This account demonstrates that she has chosen activities that distance her from the caregiving environment that surrounds Tony, rather than taking the opportunity to detail her devotion to the caring role. When Pamela removes herself from her current environment in this way, her story highlights that she had recognised that her situation had changed. This demonstrates how Pamela is storying a new identity outside of her previously described attentions to Tony as his caregiver. When Pamela also described doing these activities by herself, Pamela has indicated that she knows she will eventually be without her partner. This means she stories an identity for herself outside of partner to match her future circumstances. Pamela also makes it clear that she could not have done any of these activities prior to Tony transitioning to RAC. When Pamela included this in her account she told a story of not only how restricted her movements outside the home were prior to RAC for Tony but also how this had changed because she now had freedom and agency over her daily life to make decisions that suit her. By Pamela mentioning all the activities she is doing, she is indicating that she is making the most of this new found freedom. In this way, the re-structuring was an instrument for providing Pamela with a sense of achievement, purpose, and the chance for new social connections.

Steven, Daniel, John, and Pamela established patterns for living after transitioning the care recipient into a RAC facility. Regardless of the pathway chosen, the outcome is the same for all four participants that life is more manageable when they individually established patterns for living that suited each of them and their unique situations. This has highlighted that there is no right way of moving forward after the separation of the care recipient but that through re-structuring activities, as outlined, new identities, purpose, agency and social

connections can be achieved. In this way, life post RAC for the care recipient became less difficult.

Personal Belongings. 'Personal belongings' explored participants experiences of giving away the care recipients personal belongings from the home after they had transitioned into a RAC facility. Similar to the previous sub-narratives this happened at the two different transitional periods, after the care recipient had transitioned into a RAC facility and after the death of the care recipient. The first excerpt that explores this narrative was from Olivia who lived with Holly for 25 years. Olivia was Holly's caregiver for three and a half years until Holly transitioned into a RAC facility. Holly had been in RAC for 13 months at the start of the interview. This excerpt was chosen because it made visible a shared belief held by the participants that made the process of giving away personal belongings while the care recipient was still alive more difficult. The excerpt starts with the interviewer enquiring about the grieving process after Holly has transitioned into a RAC facility.

Int: And there's a bit of a grieving process about moving someone you care for into residential.

Olivia: Oh yeah because everything we did here was, you know, you look at the garden, and you think oh yes, we planted all that, and then you go and chop it out because it died, and you think oh well, what do you do now? Plus, I've got all her stuff and all my stuff, yeah. Anyway, I'm slowly giving it away back to the bridge club, a whole lot of her stuff and I keep doing that, I do something every week. And I think that's a good thing to get rid of it.

Int: It's difficult isn't it?

Olivia: Yeah it is. It's easier if they die because, you know, they've died so you can give it away, but you feel terrible giving it away or passing it on to the hospices or something like that. But that's where it's got to go, because you can't keep it all.

Giving away Holly's personal belongings was a challenge for Olivia because Holly was still alive but unable to give her permission for her personal belongings to be given away. Olivia is driven by the belief that a person should give permission while alive to the disposal of their personal belongings. This made the decision to give away the items a challenge for Olivia. Olivia, therefore, only began to give away Holly's personal belongings when she eventually decided she just could not keep them all. The struggle with the decision, however, was still evident because Olivia did not rush into completing the task but continued at a slow pace to give away the items. Through this practice, Olivia has shown that she has accepted her new circumstance of living without Holly. Furthermore, Olivia has taken agency of her living space by removing the items.

Another participant, Sarah told a similar story to Olivia. Sarah expressed that she was thankful that her partner was unable to return home once he transitioned into a RAC facility because she feared he would realise she had given away his belongings without his permission. When Sarah acknowledged that George would be unhappy if he realised his personal belongings had been given away, she highlighted that she believed it had been wrong for her to make the decision for removal of the items without George's permission because he was still alive. Although Sarah is afraid of what might happen if George returned home, she has accepted that he never will. This knowledge has allowed Sarah to take agency over her living space through removal of the items. By doing this, Sarah has matched her environment to her new situation of being on her own. This was a common representation among participants when the decision to give away personal belongings occurred after the

care recipient transitioned into a RAC facility. The shared belief that a person should have autonomy over their personal belongings as long as they are alive was also the main reason cited among participants for the struggle they experienced when they gave away personal belongings at this transitional point.

When personal belongings were given away after the death of the care recipient a different story was told. For the next excerpt we return to Jacob, who was first introduced under the narrative 'They said I need to'. Jacob's narration was chosen because it provided a clear example of the difference with the challenge of giving away personal belongings when the care recipient was still alive to when they had died. At the time of the interview Jacob's wife Ivy had passed away after being in a RAC facility for 11 months. The excerpt starts after Jacob has outlined the caregiving process and Ivy's symptomatic behaviour and severity.

Int: Yeah and like you say, there's less day to day stresses. It sounds like you were responsible for everything around the house involved with supporting Ivy, so I guess that …

Jacob: It's well, what I found hard at times and that's made me at times unsettled is tidying up Ivy's stuff, packing it all away, opening a drawer and still finding stuff she stored away there. Memories, her memories, and it's – mm.

Int: Yeah, difficult.

Jacob: But I think, the last of it is ready in boxes to go.

The knowledge that Ivy had died had allowed Jacob to make the decision unencumbered by thinking he needed to seek Ivy's permission. Unlike Olivia and Sarah, therefore, the decision that Jacob made is not underpinned by guilt when permission was not attained. This meant the struggle for Jacob was related to the grief of losing Ivy and re-experiencing memories of her and them as a partnership through viewing her items as he packed them away rather than

a struggle with the permission to give away the items. Furthermore, unlike Olivia and Sarah, because Jacob's wife Ivy had passed away, the exercise of packing away Ivy's personal belongings was cathartic for Jacob. This was shown in Jacob's very next comment: "It's becoming more settled and as time goes by my habits, my doings and not-doings shall become more regular, be regulated." When Jacob described this straight after his earlier comment about packing away Ivy's personal belongings Jacob indicated that tasks such as this provided him with closure.

Reordering the Home. 'Reordering the home' explored a participant's experiences when they had decided not to give away the care recipients personal belongings upon the care recipient transitioning into a RAC facility. The next excerpt was chosen because it highlighted not all participants made the decision for removal of personal belongings from the home in the same way. The next excerpt is from Sally, who cared for her husband Roy as previously discussed under 'They said I needed to'. Roy has been living in a RAC facility for three months at the start of the interview. The excerpt started after Sally told the interviewer about a friend she had whose husband had died. The friend had given away her husband's personal belongings but while completing the task she had thought of Sally and how Sally could not do that because her husband was still alive. In the interview, Sally indicated that she agreed with her friend's assessment that she could not give away Roy's personal belongings while he was still alive although she wanted to make changes to her environment. The excerpt started just after Sally had narrated her friend's story and assessment of Sally's situation.

Int: Yeah like you say, there's not that closure. (…)

Sally: No, you can't do that. I've decluttered a lot. We used to have a black shelving, quite a big piece, and it had speakers and things attached to it, and I used to sit here and look at this black thing, full of his toys because he had lots of the toys, photos, and knick knacks. Anyway, I packed up all the stuff and my son-in-law and daughter came down from [their home] and they put the shelving on skateboards and skateboarded it out to the garage. I use it for storage there now because it was getting run down. I've turned everything around and so now I can sit and look out at the garden.

Sally: I went and bought that white lowboy, it's well I've only had that about a fortnight because we had a big thing that obtruded right into the room and that sort of sits back, and the room is so much bigger and lighter. The benchtop needed replacing and I could never have contemplated [doing that] when he was home. The first thing I did was replace the benchtop out in the kitchen and it just made such a difference. It's modernised it.

Int: So, you've been able to do a few nice changes and things for yourself.

Sally: I've just decluttered, I've decluttered all that. I mean, I've still got a little clutter over there and a little bit of clutter there, but nothing like what it used to be. In the meantime, I'm more at peace I suppose and I'm finding it not difficult actually.

Sally indicated that she believed that she could not give away Roy's personal belongings completely while he was still alive. Sally, however, was unhappy with some areas of the environment that she lived in because they no longer matched with her new situation of being on her own. Sally had come to the realisation that now her living space only had to suit her.

This meant that areas that contained some of Roy's personal belongings and furniture that he had chosen while he lived there no longer had to be part of her environment if she did not want them to be. Sally's solution for resolving the dilemma was to remove the furniture and items to the garage and to buy new furniture that suited her. In this way, although Sally could not bring herself to entirely give away the items, she still exercised agency over her environment by making the space suitable for only her needs. This means that Sally has also accepted that Roy would never return home and that she would eventually be on her own. This knowledge allowed Sally to make the required changes. When Sally achieved agency over her environment, Sally experienced peace and comfort, which made the separation from Roy less difficult for her.

Olivia, Sarah, and Sally, through these shared experiences expressed how they had moved forward after the care recipient had transitioned into RAC. Through discussion of the re-arrangement of their environments they have indicated that they have accepted their new circumstance of life after separation from the care recipient. They have also taken agency over their lives by matching their environment to their new situation. Jacob has done the same although his situation is different as Ivy had passed away. This means that for Jacob when he discussed the 'personal belonging' narrative he was also expressing remembrance of Ivy.

The decision to give away personal belongings was an action that was commonly performed by the participants in this study. It was also commonly represented by participants as being challenging. Similar to Olivia, Sarah, and Jacob's accounts, the process always created some difficultly if albeit in a different manner depending on whether it was completed before or after the death of the care recipient. This was because prior to death of the care recipient there was a shared social understanding that a person should have autonomy over their personal items until their death. After death, the task changes from a

difficult decision to a cathartic exercise because this shared social understanding is no longer applicable. Also similarly to Sally's account, not every participant came to terms with the decision to give away personal belongings prior to the death of the care recipient, because of the dominance of the shared social understanding.

Chapter 7: Discussion

Shaping the Decision

The narrative analysis here highlighted a number of important factors that shaped the decision-making process for transition of the care recipient to a RAC facility. Caregivers' stories outlined a set of common factors; progression of symptom severity, challenging behaviours, and safety. Caregivers did not discuss these common factors in isolation of each other nor did they focus on one factor more than another. Instead the factors were discussed as a set that accumulated over time. When caregivers in this study arrived at a point where the set of factors were overwhelming their resources and the community resources available to them, they started the decision-making process for RAC for the care recipient. Alongside the set of factors identified in this research, the physical health of the caregiver was also a factor that significantly shaped the decision-making process. Importantly, however, when caregivers considered the set of factors it was not the factors themselves but their perception of being able to continue to manage the set that was depicted as determining the decision for transition.

These findings draw attention to the individual nature of symptoms experienced and the unique ways in which caregivers manage those symptoms. A narrative approach also allowed for an uncovering of the implicit that sat behind the caregiver's story, which highlighted the caregiver's subjective reality within a relational context, both personally and socially (Breheny et al., 2019). This was important for understanding the decision-making process as caregivers' experiences were not only situated around the care recipient but also connected to a wider social context (Fitzpatrick & Grace, 2019; Kiwi et al., 2017; Lethin et al., 2015). In this way, this research highlighted a framework of nuanced aspects to be considered. These nuanced aspects provide a broader representation of the situation. This

means a more comprehensive framework for understanding the caregiver experience of transitioning the care recipient to RAC is obtained.

Previous research on the experience of caregiving tends to emphasise a particular factor or factors in isolation, for example, research that explores carer burden and role strain. Research on carer burden and role strain generalises that when these factors increase then the likelihood of transition to RAC increases (Cheng, 2017; Givens et al., 2014; Liu et al., 2017; Reed et al., 2014; Richardson et al., 2013; Shaji et al., 2009). Although this type of research outlines an important part of the caregiver experience this study has shown that it does not provide a comprehensive framework because it is too simplistic in the information it provides.

Social Context of RAC

The strength of the socially shared understanding that RAC facilities are a last resort option is evident throughout this study. The stories that participants told of resistance to RAC and justification for RAC demonstrates this. Caregivers also told stories of compromising their own well-being and tolerating levels of health that previously they would not have deemed acceptable due to their resistance to transition the care recipient to RAC. This level of resistance implies that caregivers do not consider RAC facilities a desirable living option for the care recipient. This reflects socially shared narratives of RAC that caregivers use to situate their decision-making.

There is a common shared social understanding that RAC facilities are unattractive places that reduce autonomy and freedom (Bitner, 2019; Löfqvist et al., 2013; Warburton & Savy, 2012). Caregivers are also frequently exposed to media that represent RAC facilities as places that provide substandard care (Jones, 2018; Russell & Nightingale, 2019).
Both of these aspects are important considerations for caregivers when the decision for RAC is evaluated. Caregivers feel an obligation and responsibility to the care recipient to make

sure that they receive the best care available while being treated with dignity and respect (Fitzpatrick & Grace, 2019; Lethin et al., 2016; Punty and Foli, 2019). When transitioning a care recipient to RAC, therefore, caregivers do not want to feel as if they have abandoned their obligations and responsibilities by transitioning the care recipient to a place where it is suggested that they will get treated inappropriately while receiving substandard care (Bitner, 2019; Jones, 2018; Löfqvist et al., 2013; Russell & Nightingale, 2019). When RAC facilities are negatively represented, therefore, it shapes beliefs that provide a framework for a context of guilt and this appears to underpin the stories that caregivers told about why they resisted RAC and justified their decision after the care recipient entered RAC.

Recognition of caregivers' guilt is not new in research as many studies have highlighted its existence. For instance, when guilt in caregivers was explored by Prunty and Foli (2019) they concluded that caregivers feel guilty because they perceive their performance as inadequate and/or that they had violated a moral code that they hold for themselves in regards to the care recipient. Caregivers in this study felt a moral obligation towards the care recipient especially when the relationship had been a long-term loving and reciprocal partnership. The perceived moral obligation included looking after and keeping the care recipient safe and in their own home. When the caregiver could no longer maintain this level of care they felt they had morally let that person down. Gallego-Alberto et al., (2020) explored guilt among family caregivers and expanded the boundaries to include the guilt that caregivers feel because of pressure exerted from other people including the care recipient. The pressure exerted from the care recipient was described as complaints and comments from the care recipient that indicated the caregiver was not doing an adequate job in looking after them. For instance, one caregiver wanted to leave the house and the care recipient suggested the caregiver was abandoning her. The pressure exerted from other people in this study was described as complaints and comments that other family members made about the quality of

caregiving provided by the caregiver. For example, one caregiver was asked by family members what she had done to cause her mother's aggressive behaviour. This thesis supports the existence of guilt while also providing a context for what creates guilt. That is, that it is built on shared social understandings of RAC facilities.

Social Context of Personal Autonomy

A second shared social understanding is that care recipients should have autonomy over personal belongings until their death. This expectation also made life difficult for caregivers after the care recipient transitioned to a RAC facility. The dominant social understanding that people should have autonomy over their personal belongings was so strong that for some of the caregivers they could not proceed as they would have ideally liked to after the care recipient entered RAC. Prior research has linked personal belongings to a person's identity and their place in the home (Rowles, Oswald, & Hunter, 2003; Van Steenwinkel, Baumers, & Heylighen, 2012). This is because personal belongings provide memories, support significance, and tell a story of experiences (Falk, Wijk, Persson, & Falk, 2012). Personal belongings, therefore, not only represent where a person belongs but also provide a summary of the owner and a timeline of their past social interactions (Falk et al., 2012; Rowles et al., 2003; Van Steenwinkel et al., 2012).

What has been missing from this literature, up until the present research is the caregivers' perspective. What this study highlights is that although caregivers' cherish these items for their connection to the care recipient there comes a time when they feel the need to have them removed from the home. Caregivers accounted for this in terms of practical considerations or emotional reasons. Caregivers, where the care recipient was living in RAC, described how there was either not enough room in the home for all of their items and the care recipient's items, or they wanted to re-structure the home to suit their own needs. For caregivers where the care recipient had passed away, the changes were relevant for finding

closure. For many caregivers the changes were also connected to realising that their situation had changed and that the new situation required them to form a new identity outside of caregiver, spouse, partner, or co-residing companion. A part of forming this new identity was linked to changing the environment in which they lived by making changes that they deemed suitable and necessary. In this way, often the changes in the environment provided comfort, agency and purpose during this difficult transitional process.

The different caregiver responses after transitioning the care recipient to RAC or after the bereavement of the care recipient point to the individual caregiver circumstances and their own requirements because of those circumstances. Where the care recipient was still living, however, responses were all shaped by the struggle around the care recipient's right to autonomy over their personal belongings until death.

Managing Guilt

This study demonstrates the enormous effort it takes to daily manage a situation that often ultimately becomes unmanageable, regardless of the caregiver, their situation or their ability. In this way, what this study draws attention to is how caregivers initially were resistant to transitioning the care recipient to a RAC facility but that it eventually became a story of necessity. Once the care recipient moved into RAC, however, the caregivers' beliefs changed. Retrospectively, caregivers frequently realised that the RAC facility was the appropriate option both for them and for the care recipient. Once caregivers had this realisation the initial guilt that they felt became manageable because they believed they had made the right decision. Through their stories about the transition, they described putting their guilt and struggle into a broader story about their experience of caregiving.

The findings from this study, however, supported that future planning for RAC was an important consideration for caregivers if they are to attain a sense of having made the right decision. Caregivers often felt that they had made the right decision when they believed the

RAC facility provided adequacy of care provision. When a care recipient experienced an adverse health event and no future planning had been completed, a rushed decision was made. The rushed decision did not provide a framework to assess the adequacy of care provision as the caregiver was unable to choose a suitable RAC facility in a short period of time. This finding supports research already completed by Brown, (2012), and Fitzpatrick and Grace, (2019) that reviewed outcomes of the rushed decision process in their studies. These studies both had a similar conclusion that the rushed decision process led to the first available bed being chosen even when the RAC facility was deemed unsuitable for provision of care. What this study adds to this body of research is that it demonstrated that caregivers who had the opportunity to consider that transitions to care might be needed, describe more competence in making their decision. They felt that the care they organised was adequate, which helped caregivers feel they made the right decision.

The present study also highlighted that guilt was less prevalent when health professionals accepted responsibility for the decision of the care recipient moving to an RAC facility. The responsibility, however, was only relinquished if the caregiver was able to establish trust that the health professional was competent in the dementia field. This finding agrees with research by Chene (2006) and De Vreese et al., (2016) that health professionals need to be well-trained to be trusted by caregivers as competent. Furthermore, there is a body of research that suggests that trust is only established through long-term alliances, collaboration from both parties, and good communication (Boogaard, Werner, Zisberg, & Van Der Steen, 2017; Skirbekk, Middelthon, Hjortdahl, Finset, 2011; Zegwaard, Aartsen, Grypdonck, & Cuijpers, 2017). This study showed that trust was also established from direct observation of the care recipient's condition and situation when it matched what the health professional was recommending.

The use of diaries is another instrument that can re-position guilt. Dairies became relevant when caregivers were struggling to maintain a stance where guilt had previously been vanquished. In this situation, diaries in this study stand out as a valuable tool because they highlight the minutiae of the caregiving role that can be forgotten. In this way, a caregiver can remember all that they did, which validates their nuanced experience and, therefore, returns them back to their original stance that RAC was a necessary option. Prior research has used diaries as a way of recording experiences that are later analysed. In these studies, diaries were used as a resource to capture the finer details of the experiences and provide a reflective tool for those experiences. Breheny, Horrell, & Stephens (2020) used diaries in this capacity to provide information during repeated interviews of the caregiving experience. Similarly, Jayalath, Ashaye, & Kvavilashvili (2016) had family caregivers complete daily dairies for a week as part of their investigation into family caregiver experiences. This study has demonstrated the use of diaries in real life practice, highlighting how the use of diaries does not just capture experiences or provide a reflective tool but that they are also instrumental in helping a caregiver remain confident in the decisions they have made.

Future Directions For Research

The participants' experiences although nuanced were often similar in content and function. This may have occurred because the participants were all from the same ethnic group (European/Pākehā), which meant they may have had similar shared characteristics including cultural practices and beliefs and expectations around ageing and dementia care (Ministry of Health, 2004; Unger, 2011). Therefore, research with other ethnicities that have different cultural practices in relation to dementia care would provide a broader spectrum of experiences, social context, and meanings. This is specifically relevant in NZ where Māori have a different worldview of caregiving to Pākehā. Māori view caregiving from a collective

perspective where frequently they pool resources within whānau, hapu, and iwi to provide care (Dudley et al., 2019). The collective approach differs from Pākehā caregiving that is frequently based on a individualistic model (Podsiadlowski & Fox, 2011). Pākehā may be more likely to structure care around a primary caregiver and may experience limited support for caregiving from extended family members (Horrell, Stephens, & Breheny, 2015). Furthermore, Māori may be less likely to identify with a Western biological model of medicine than Pākehā. This is because Māori often identify with a holistic approach that includes spirituality, which is not an approach that is accounted for under the Western biological model of medicine (Dudley et al., 2019; Townsend, 2011). This means that Māori may be less likely to seek help from organisations that provide care resources for dementia if they are underpinned by a Western biological medical model (Townsend, 2011). Because of this Māori have access to different resources and knowledge surrounding provision of care. As Māori may utilise different resources and may have a different approach to caregiving it is possible that Māori caregiving experiences could be different to Pākehā caregiving experiences.

The caregivers and care recipients in this study were also in long-term co-residing relationships. When people have lived together for a long time they not only share a history of memories but also they establish a co-joined identity (Wallerstein, 2019). These aspects shape the decision-making process**.** This was demonstrated in this study through caregivers having prior knowledge of what their care recipient had experienced in their life and using this as a memory to cement their decision as being right for that person. The same aspects also influenced caregiver experiences after the care recipient had passed away. This was demonstrated in this study by the re-establishment of the caregivers as solo identities as a significant step to their re-structuring process. It could, therefore, be advantageous for future research to go beyond this boundary by investigating transitions to RAC outside of a long-

term living arrangement where a co-joined identity has not been established. For example, research could explore caregiving relationships between friends, where independent identities are established. An established independent identity prior to the caregiving role might result in different obligations and responsibilities being considered when decisions are made. If there are different obligations and responsibilities before the decision for RAC is made, then different impacts for the caregiver are likely after the decision is made. Likewise, a different restructuring process may be experienced after the transition for these kinds of caregiving situations. Exploring friend caregiving relationships could also be important for future research as more people are reaching older ages single or living alone. This is especially common among women who are more likely to experience the loss of a spouse or partner (United Nations, 2020). Because of this, friends as caregivers may become more prevalent.

The current study aimed to explore and give voice to caregiver experiences. This was done in a retrospective manner as the care recipients were already living in an RAC facility and some of them had also already passed away. Narratives can shift over time as new knowledge replaces previous understandings (Weir, 2012). This was demonstrated in this study when participants changed their perspective of RAC facilities from one of resistance to one of acceptance when they realised RAC facilities were not as they had first believed. Furthermore, as this study has shown through the discussion on diaries, memories can also fade or change, which can also alter narratives. Similarly, emotions are likely to be described in a less intense manner. It could be beneficial, therefore, for future research to study caregiver experiences at the time that these transitional points are taking place. This could result in narratives being described in finer and more acute detail and with more emotion involved. This highlights that there is a possibility that narratives that are retrospectively explored could be different from those that were captured prospectively.

This study also utilised a single interview process, which provided a snapshot of lived experienced specific to a retrospective study. This retrospective sense-making regarding the transition was the focus of sustained analysis. Future research may consider using repeated interviews to capture change over time whilst allowing the participants opportunities to reflect on changes as they happen (Saldaña, 2003). Repeated interviews also increase the quality of the relationship between researcher and participants (Vincent, 2013). This type of interviewing process; therefore, would allow greater opportunities for the development of understandings about multiple identities and shifting narratives (Saldaña, 2003; Vincent, 2013). This does not mean, however, that the experiences and narratives that were presented in this study are any less authentic. Narrating decision-making and transitions in retrospect just provides a different perspective from a different vantage point. Examining decision-making as it unfolds would broaden the perimeters to investigate caregiver's current knowledge of experiences. In this way, further nuanced experience and meanings could be represented during and across the transitional points.

Another point for consideration is that all participants were recruited from regional service providers associated with Alzheimers' NZ or Dementia NZ. These are charitable trusts providing dementia-specific services, advice, information, and education nationwide, tailored dependent on their resources, location and clients. When this occurs, it needs to be considered if a specific demographic of individuals might contact these types of organisations. Literature highlights that lower socio-economic status, not having English as a first language, employment status, and geographical location can all influence whether individuals contact these types of health organisations (Health Quality and Safety Commission New Zealand, 2020; McMaughan, Oloruntoba, & Smith, 2020; Meuter, Gallois, Segalowitz, Ryder, & Hocking, 2015; National Health Committee, 2010). The majority of the participants referred to their relationship with their local dementia organisation during their

interview. Frequently, this resulted in caregivers implementing parts of the care model that were supported by this type of organisation. In all cases where this information was implemented, caregivers spoke of how this information had been beneficial for care provision. Moreover, many participants felt supported and not alone when they had a case worker from one of these organisations that supported them. In this way, this study highlights a supported group of caregivers. It is likely that there are different narratives not presented here because of the type of convenience sample recruited. For example the 'hidden' caregivers could be coping well without this support or they could be facing more challenges because they cannot access or do not feel they belong within these service models. Because of this caregiver experiences where there is no connection to an organisation could be quite different. It would, therefore, be expedient for future research to explore caregivers' experiences outside of those that are connected to regional service providers if a greater understanding of this transitional point is to be achieved.

A final point for consideration is that the original interviews were completed for a sleep study (Gibson, & Gander, 2020). This will have shaped the stories that participants told. The present study goes beyond the boundary of sleep associated with dementia caregiving. When taking this into consideration, it is relevant to note that the original interviews were semi-structured frequently using open ended questions **(**See Appendix D**).** Furthermore, the interviewer regularly invited background content and context outside of the sleep arena. This allowed for a large amount of information to be supplied that was outside of the sleep context but relevant to a study on the dementia caregiving experience. Participants also regularly used the questions as opportunities to shift the interview away from sleep into the broader context of dementia caregiving. In this way, what this study has highlighted is key factors in dementia caregiving such as safety, access to services, behavioural and symptomatic features that open up new opportunities for research to explore in greater detail in the future.

Future Implications for Practice

During this study it has been highlighted that resistance to RAC facilities occurred mainly because of negative shared social understandings of RAC facilities. This resistance has implications for the caregiver as outlined in this study. When this study is taken into consideration, it will provide a platform of understanding of what is involved and underpins the resistance. In this way, health professionals working in this field may find the results of this study provides a framework for understanding these decisions and addressing caregivers' concerns. This means health professionals maybe able to address these concerns in a more targeted way.

Additionally, this study has highlighted the challenges and complexities of the caregiver experience and how that experience is unique to each situation. This study, therefore, demonstrates the nuanced experience and how that nuanced experience is important in understanding a caregiver's journey before and after transitioning a care recipient to a RAC facility. In this way, this study can provide people involved with dementia care a foundation for the understanding of the necessity of a person-centred approach.

Conclusion

This study has provided important evidence around caregivers experiences of complex and challenging situations and their ability to manage within this environment. As that environment has been shown to become progressively more difficult eventually, all caregivers in this study had to navigate the process of making the decision to transition the care recipient to a RAC facility. Caregivers made these decisions because of the changing needs of the care recipient and their changing situations. Although transitions to RAC were not viewed as ideal, caregivers described it as the most appropriate option given the circumstances. This study has drawn attention to the shared social understandings that underpin caregivers' decisions and how these shared social understandings create a context of

guilt that shapes the decision-making process. In this way, this study provides a greater understanding of caregiver decisions prior to and after the decision for RAC for the care recipient is made. Such knowledge is valuable for informing health and social care professionals to support caregivers at this complex time.

References

Afram, B., Verbeek, H., Bleijlevens, M. H., Challis, D., Leino-Kilpi, H., Karlsson, S., … Hamers, J. P. (2014). Predicting institutional long-term care admission in dementia: a mixed-methods study of informal caregivers' reports. *Journal of Advanced Nursing*, *71*, 1351-1362.

Age Concern New Zealand. (n.d.). Home support. Retrieved from https://www.ageconcern.org.nz/ACNZ_Public/Home_support.aspx

Alzheimers Association. (2020). Alzheimers and Dementia. Retrieved June 2, 2020, from https://www.alz.org

Alzheimers New Zealand. (2016). *The later stages of dementia and end of life care: A guide for people with dementia and their family/whānau*. Retrieved from https://www.alzheimers.org.nz/getattachment/About-Dementia/Booklets-and-fact-sheets/Booklet-6-The-later-stages-and-end-of-life-care.pdf/

Alzheimers New Zealand. (2019). What is dementia. Retrieved November 18, 2019, from https://www.alzheimers.org.nz/information-and-support/information/what-is-dementia

Alzheimers Research UK. (2018). Symptoms. Retrieved October 11, 2019, from https://www.alzheimersresearchuk.org/about-dementia/helpful-information/symptoms/

Alzheimers Society. (2018). *Positive language: An Alzheimer's Society guide to talking about dementia*. Retrieved from https://www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf

Andrieu, S., Bocquet, H., Joel, A., Gillette-Guyonnet, S., Nourhashemi, F., Salva, A., & Grand, A. (2005). Changes in informal care over one year for elderly persons with Alzheimer's disease. *Journal of Nutrition, Health & Aging*, *9*, 121-126.

Baer. (2017). *When binary thinking is involved, polarization follows*. Retrieved from https://www.psychologytoday.com/us/blog/empathy-and-relationships/201701/when-binary-thinking-is-involved-polarization-follows

Bellantonio, S., Kenny, A. M., Fortinsky, R. H., Kleppinger, A., Robison, J., Gruman, C., … Trella, P. M. (2008). Efficacy of a geriatrics team intervention for residents in dementia-specific assisted living facilities: Effect on unanticipated transitions. *Journal of the American Geriatrics Society*, *56*, 523-528.

Bitner, G. (2019). *The 'home'/'homelessness' continuum in residential aged care* (Doctoral dissertation, Queensland University of Technology, Brisbane, Australia). Retrieved from https://eprints.qut.edu.au/128714/2/Grace_Bitner_Thesis.pdf

Bloomfield, A. (2020). Maximum contribution applying in each territorial local authority region from 1 July 2020. Retrieved November 9, 2020, from https://gazette.govt.nz/notice/id/2020-go2874

Bo, C. (2015). Social constructivism of language and meaning. *Croatian Journal of Philosophy*, *15*, 87-113.

Bold, C. (2011). What is Narrative. In *Using narrative in research* (pp. 15-31). Thousand Oaks, CA: Sage.

Boogaard, J. A., Werner, P., Zisberg, A., & Van der Steen, J. T. (2017). Examining trust in health professionals among family caregivers of nursing home residents with advanced dementia. *Geriatrics & Gerontology International*, *17*, 2466-2471.

Breen, L., & Darlaston-Jones, D. (2010). Moving beyond the enduring dominance of positivism in psychological research: Implications for psychology in Australia. *Australian Psychologist*, *45*, 67-76.

Breheny, M., Horrell, B., & Stephens, C. (2019). Caring for older people: Relational narratives of attentiveness, commitment and acceptance. *International Journal of Care and Caring*, *4*, 201-214.

Breheny, M., Horrell, B., & Stephens, C. (2020). A participatory journal/dialogue approach to narrative research illustrated using a study of informal caregiving. *Qualitative Research in Psychology*. Advance online publication. doi: 10.1080/14780887.2020.1716423

Brindle, N., & Holmes, J. (2005). Capacity and coercion: Dilemmas in the discharge of older people with dementia from general hospital settings. *Age and Ageing*, *34*, 16-20.

Broad, J. B., Ashton, T., Gott, M., McLeod, H., Davis, P. B., & Connolly, M. J. (2015). Likelihood of residential aged care use in later life: A simple approach to estimation with international comparison. *Australian and New Zealand Journal of Public Health*, *39*, 374-379.

Brodaty, H., & Berman, K. (2015). Interventions for Family Caregivers of People with Dementia. In R. T. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing* (pp. 549-570). Chichester, England: John Wiley & Sons.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*, 217-228.

Brown, J. (2012). *The most difficult decision: Dementia and the move into residential aged care*. Retrieved from https://www.dementia.org.au/files/20121016-NSW-PUB-Moving_To_Res_Care.pdf

Bruner, J. S. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.

Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist*, *46*, 52-61.

Burns, C., Archbold, P., Stewart, B., & Shelton, K. (1993). New diagnosis: Caregiver role strain. *International Journal of Nursing Terminologies and Classifications*, *4*, 70-76.

Burr, V. (2006). *An introduction to social constructionism*. New York, NY: Routledge.

Burr, V. (2015). *Social constructionism* (3rd ed.). New York, NY: Routledge.

Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, *3*, 73.

Cheek, J., & Ballantyne, A. (2001). Moving them on and in: The process of searching for and selecting an aged care facility. *Qualitative Health Research*, *11*, 221-237.

Cheek, J., Ballantyne, A., Byers, L., & Quan, J. (2006). From retirement village to residential aged care: What older people and their families say. *Health and Social Care in the Community*, *15*, 8-17.

Chene, B. (2006). Dementia and residential placement. *Qualitative Social Work: Research and Practice*, *5*, 187-215.

Cheng, S. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, *19*(9), 64.

Collins, A., & Willson, G. (2008). *Maori and informal caregiving*. Retrieved from https://www.moh.govt.nz/notebook/nbbooks.nsf/0/933A5FFFCE411AFECC2579A5006B42E3/$file/maori-informal-caregiving-apr08.pdf

Connolly, M. J., Broad, J. B., Boyd, M., Kerse, N., & Gott, M. (2013). Residential aged care: The de facto hospice for New Zealand's older people. *Australasian Journal on Ageing*, *33*, 114-120.

Corey, K. L., & McCurry, M. K. (2017). When caregiving ends: The experiences of former family caregivers of people with dementia. *The Gerontologist*, *58*, 87-96.

Corrada, M. M., Brookmeyer, R., Paganini-Hill, A., Berlau, D., & Kawas, C. H. (2010). Dementia incidence continues to increase with age in the oldest old: The 90+ study. *Annals of Neurology*, *67*, 114-121.

Couture, M., Ducharme, F., Sasseville, M., Bradette, C., & Gaudet, K. (2020). A qualitative systematic review of factors affecting caregivers' decision-making for care setting placements for individuals with dementia. *Geriatric Nursing*, *41*, 172-180.

Cranwell, C. (2016). *Navigating Alzheimer's: Survival secrets of a long term carer*. Victoria, Australia: Global Publishing Group.

Crawford, K., Digby, R., Bloomer, M., Tan, H., & Williams, A. (2014). Transitioning from caregiver to visitor in a long-term care facility: The experience of caregivers of people with dementia. *Aging & Mental Health*, *19*, 739-746.

Crossley, M. (2008). Narrative analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 131-144). London, England: Sage.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks: Sage.

Croucher, M., Duncan, C., Fisher, M., Fox, C., Hosford, I., Malone, D., … Worrall, R. (2011). *The use of antipsychotics in residential aged care*. Retrieved from https://bpac.org.nz/a4d/resources/docs/RANZCP_clinical_recommendations.pdf

Cusack, S. A., & Thompson, W. J. (2013). *Leadership for older adults: Aging with purpose and passion*. New York, NY: Routledge.

Davies, S., & Nolan, M. (2003). 'Making the best of things': Relatives' experiences of decisions about care-home entry. *Ageing and Society*, *23*, 429-450.

De Vreese, L. P., Salvatore, L., Rovesta, L., & Fabbo, A. (2016). The management of dementia in primary care. In O. Capelli (Ed.), *Primary care in practice: Integration is needed* (pp. 69-92). Croatia, Europe: Intech.

Dellasega, C., & Nolan, M. (1997). Admission to care: Facilitating role transition amongst family carers. *Journal of Clinical Nursing*, *6*, 443-451.

Didham, R., & Cheung, J. (2011). New Zealand's cohort life expectancies in a global context. *New Zealand Population Review*, *37*, 145-157.

Doyle, C., & Roberts, G. (2017). *Moving into residential care: A practical guide for older people and their families*. London, NY: Jessica Kingsley.

Ducharme, F., Couture, M., & Lamontagne, J. (2012). The role of health care professionals in the decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Management & Practice*, *24*, 283-291.

Dudley, M., Menzies, O., Elder, H., Nathan, L., Garrett, N., & Wilson, D. (2019). Mate wareware: Understanding 'dementia' from a Māori perspective. *New Zealand Medical Journal*, *132*, 66-74.

Efran, J. S., McNamee, S., Warren, B., & Raskin, J. D. (2013). Personal Construct Psychology, Radical Constructivism, and Social Constructionism: A Dialogue. *Journal of Constructivist Psychology*, *27*, 1-13.

Falk, H., Wijk, H., Persson, L., & Falk, K. (2012). A sense of home in residential care. *Scandinavian Journal of Caring Sciences*, *27*, 999-1009.

Feldman, M. S., Sköldberg, K., Brown, R. N., & Horner, D. (2004). Making sense of stories: A rhetorical approach to narrative analysis. *Journal of Public Administration Research and Theory*, *14*, 147-170.

Fitzpatrick, K., & Grace, M. (2019). Dementia patients' transition to residential aged care: Carers' and social workers' experiences. *Australian Social Work*, *72*, 287-298.

Galbin, A. (2014). An introduction to social constructionism. *Social Research Reports*, *26*, 82-92.

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M. D., & Márquez-González, M. (2020). "I feel guilty". Exploring guilt-related dynamics in family caregivers of people with dementia. *Clinical Gerontologist*. Advance online publication. doi: 10.1080/07317115.2020.1769244

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003). Caregiving and institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, *43*, 219-229.

Gaugler, J. E., Yu, F., Davila, H. W., & Shippee, T. (2014). Alzheimer's disease and nursing homes. *Health Affairs*, *33*, 650-657.

Gibson, R., & Gander, P. (2020). Factors associated with the sleep of carers: A survey of New Zealanders supporting a family member with cognitive impairment or dementia. *Dementia*. doi: 10.1177/1471301220915071.

Givens, J. L., Mezzacappa, C., Heeren, T., Yaffe, K., & Fredman, L. (2014). Depressive symptoms among dementia caregivers: Role of mediating factors. *The American Journal of Geriatric Psychiatry*, *22*, 481-488.

Givens, J. L., Selby, K., Goldfeld, K. S., & Mitchell, S. L. (2012). Hospital transfers of nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*, *60*, 905-909.

Greenwood, N., Habibi, R., & Mackenzie, A. (2012). Respite: carers' experiences and perceptions of respite at home. *BMC Geriatrics*, *12*(1), 42.

Haikio, K., Sagbakken, M., & Rugkasa, J. (2019). Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Services Research*, *19*(635).

Harrison, J. K., Walesby, K. E., Hamilton, L., Armstrong, C., Starr, J. M., Reynish, E. L., … Shenkin, S. D. (2017). Predicting discharge to institutional long-term care following acute hospitalisation: A systematic review and meta-analysis. *Age and Ageing*, *46*, 547-558.

Health Quality and Safety Commission New Zealand. (2020). Health service access. Retrieved October 16, 2020, from https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/health-service-access/

Herewiri, N. (2018). *Māori communities raising children: The roles of extended whānau in child rearing in Māori society*. Retrieved from https://www.borrinfoundation.nz/research-and-publications

Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers for older people. *Health Psychology*, *34*, 339-348.

Jackson, M. N., & Gaugler, J. E. (2015). Family involvement in long-term residential care. In G. D. Rowles & P. B. Teaster (Eds.), *Long-term care in an aging society: Theory and practice* (pp. 89-114). New York, NY: Springer.

Jacobs, B. J. (2006). *The emotional survival guide for caregivers: Looking after yourself and your family while helping an aging parent*. New York, NY: Guilford.

Jansen, L., Forbes, D. A., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S., … Leipert, B. (2009). Formal care providers' perceptions of home- and community-based services: Informing dementia care quality. *Home Health Care Services Quarterly*, *28*, 1-23.

Jayalath, D., Ashaye, K., & Kvavilashvili, L. (2016). Carers' diaries in dementia: Is there a role in clinical practice? *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, *4*, 94-98.

Jones, N. (2018, March 24). Rest homes investigation: Bedsore deaths, expired medication, hungry residents. *NZ Herald* [Auckland].

Kenealy, H. (2020). Alzheimer's disease. Retrieved September 18, 2020, from https://www.healthnavigator.org.nz/health-topics/alzheimers-disease/

Kitching, D. (2015). Depression in dementia. *Australian Prescriber*, *38*, 209-211.

Kiwi, M., Hydén, L., & Antelius, E. (2017). Deciding upon transition to residential care for persons living with dementia: Why do Iranian family caregivers living in Sweden cease caregiving at home? *Journal of Cross-Cultural Gerontology*, *33*, 21-42.

Knapp, M., Chua, K., Broadbent, M., Chang, C., Fernandez, J., Milea, D., … Hayes, R. D. (2016). Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: Findings from a large London case register. *BMJ Open*, *6*(11), 1-15.

Kraijo, H., De Leeuw, R., & Schrijvers, G. (2014). How spouses evaluate nursing home placement of their demented partner: A study about the end of perseverance time. *Scandinavian Journal of Caring Sciences*, *29*, 101-109.

Krull, A. C. (2013). Health care professionals, friends, family, and God: Interactions contributing to caregivers' long-term care decisions. *Sociological Spectrum*, *33*, 329-340.

Kwak, Y. T., Yang, Y., & Koo, M. (2017). Anxiety in dementia. *Dementia and Neurocognitive Disorders*, *16*, 33-39.

Kwon, S., & Tae, Y. (2012). Nursing home placement: The process of decision making and adaptation among adult children caregivers of demented parents in Korea. *Asian Nursing Research*, *6*, 143-151.

LaMantia, M. A., Stump, T. E., Messina, F. C., Miller, D. K., & Callahan, C. M. (2016). Emergency department use among older adults with dementia. *Alzheimer Disease & Associated Disorders*, *30*, 35-40.

Larkin, M. (2009). Life after caring: The post-caring experiences of former carers. *British Journal of Social Work*, *39*, 1026-1042.

Lee, D., Morgan, K., & Lindesay, J. (2007). Effect of institutional respite care on the sleep of people with dementia and their primary caregivers. *Journal of the American Geriatrics Society*, *55*, 252-258.

Leocadie, M., Roy, M., & Rothan-Tondeur, M. (2018). Barriers and enablers in the use of respite interventions by caregivers of people with dementia: An integrative review. *Archives of Public Health*, *76*(1), 72.

Lethin, C., Hallberg, I. R., Karlsson, S., & Janlöv, A. (2015). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences*, *30*, 526-534.

Liu, H., Yang, C., Wang, Y., Hsu, W., Huang, T., Lin, Y., … Shyu, Y. L. (2017). Balancing competing needs mediates the association of caregiving demand with caregiver role strain and depressive symptoms of dementia caregivers: A cross-sectional study. *Journal of Advanced Nursing*, *73*, 2962-2972.

Löfqvist, C., Granbom, M., Himmelsbach, I., Iwarsson, S., Oswald, F., & Haak, M. (2013). Voices on relocation and aging in place in very old age - a complex and ambivalent matter. *The Gerontologist*, *53*, 919-927.

Marins, A. M., Hansel, C. G., & Da Silva, J. (2016). Behavioral changes of elderly with Alzheimer's disease and the burden of care for the caregiver. *Anna Nery School - Journal of Nursing*, *20*, 352-356.

Massey University. (2019). Additional resources for NVivo. Retrieved from https://www.massey.ac.nz/massey/staffroom/national-shared-services/information-technology-services/help/training-resources-for-staff/nvivo-additional-resources.cfm

McKechnie, R., Jaye, C., Hale, B., Tordoff, J., Robertson, L., Simpson, J., & Butler, M. (2018). Transition into Care: Experiences of the elderly as they move to residential aged care. *Sites*, *15*, 16-39.

McKernan, S. (2019). *Aged residential care funding model review*. Retrieved from https://tas.health.nz/assets/Health-of-Older-People/ARC-Funding-Model-Review-Final-Report.pdf

McMaughan, D. J., Oloruntoba, O., & Smith, M. L. (2020). Socioeconomic status and access to healthcare: Interrelated drivers for healthy aging. *Frontiers in Public Health*, *8, 1-9*.

Meuter, R. F., Gallois, C., Segalowitz, N. S., Ryder, A. G., & Hocking, J. (2015). Overcoming language barriers in healthcare: A protocol for investigating safe and effective communication when patients or clinicians use a second language. *BMC Health Services Research*, *15*(1), 1-5.

Miller, E. A., Tyler, D. A., Rozanova, J., & Mor, V. (2012). National newspaper portrayal of U.S. nursing homes: Periodic treatment of topic and tone. *Milbank*, *90*, 725-761.

Ministry of Health. (2004). *Ethnicity Data Protocols for the Health and Disability Sector*. Retrieved from https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/tkhm/tumuaki/docs/ethnicity-data-protocols.pdf

Ministry of Health. (2017). *The Treasury: Budget 2017 information Release*. Retrieved from https://www.treasury.govt.nz/sites/default/files/2017-11/b17-3713993.pdf

Ministry of Health. (2018). What you can expect from home support services. Retrieved September 18, 2020, from https://www.health.govt.nz/your-health/services-and-support/health-care-services/services-older-people/what-you-can-expect-home-support-services

Ministry of Health. (2019). Funded family care questions and answers. Retrieved November 27, 2019, from https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care/funded-family-care-questions-and-answers#9

Miskovski, K. (2017). *Relationships and dementia*. Retrieved from https://www.dementia.org.au/files/NSW/documents/Discussion%20Paper%20Relationships%20and%20Dementia.pdf

Mlinac, M. E., & Feng, M. C. (2016). Assessment of activities of daily living, self-care, and independence. *Archives of Clinical Neuropsychology*, *31*, 506-516.

Moreno-Cámara, S., Palomino-Moral, P., Moral-Fernández, L., Frías-Osuna, A., Parra-Anguita, L., & Del-Pino-Casado, R. (2019). Perceived needs of the family caregivers of people with dementia in a Mediterranean setting: A qualitative study. *International Journal of Environmental Research and Public Health*, *16*(6), 1-12.

Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology*, *5*, 337-347.

Murray, M. (2003). Narrative psychology and narrative analysis. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 95-112). Washington, DC: American Psychological Association.

Murray, M. (2008). Narrative Psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 111-132). London, England: Sage.

Murray, M. (2018). Narrative data. In U. Flick (Ed.), *Sage handbook of qualitative data collection* (pp. 264-279). London, England: Sage.

National Health Committee. (2010). *Rural health: Challenges of distance opportunities for innovation*. Retrieved from https://www.moh.govt.nz/notebook/nbbooks.nsf/0/A06B332FA631554BCC2576C00008CE96/$file/rural-health-challenges-opportunities.pdf

Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2014). Literature review: Use of respite by carers of people with dementia. *Health & Social Care in the Community*, *23*, 51-63.

Neville, C. C., & Byrne, G. J. (2008). Effect of a residential respite admission for older people on regional Queensland family carers. *Collegian*, *15*, 159-164.

New Zealand Aged Care Association. (2010). *Aged Residential Care Service Review*. Retrieved from https://nzaca.org.nz/wp-content/uploads/2020/03/ARSCR-Full-Report.pdf

New Zealand Labour Party and Green Party of Aotearoa New Zealand. (2010). *A report into aged care: What does the future hold for older New Zealanders?*. Retrieved from https://www.mentalhealth.org.nz/assets/Dig-deeper/A-report-into-Aged-care.pdf

Nikzad-Terhune, K. A., Anderson, K. A., Newcomer, R., & Gaugler, J. E. (2010). Do trajectories of at-home dementia caregiving account for burden after nursing home placement? A growth curve analysis. *Social Work in Health Care*, *49*, 734-752.

Nourhashémi, F., Andrieu, S., Sastres, N., Ducassé, J. L., Lauque, D., Sinclair, A. J., … Vellas, B. J. (2001). Descriptive analysis of emergency hospital admissions of patients with Alzheimer disease. *Alzheimer Disease and Associated Disorders*, *15*, 21-25.

Ortlieb, E., & Cheek, E. H. (2013). *Advanced literacy practices: From the clinic to the classroom*. London, England: Emerald Group.

Packer, M. J. (1985). Hermeneutic inquiry in the study of human conduct. *American Psychologist*, *40*, 1081-1093.

Paulus, A. T., Van Raak, A., & Keijzer, F. (2005). Informal and formal caregivers' involvement in nursing home care activities: impact of integrated care. *Journal of Advanced Nursing*, *49*, 354-366.

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., … Henderson, S. R. (2010). The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology*, *29*, 640-659.

Penrod, J., Hupcey, J. E., Shipley, P. Z., Loeb, S. J., & Baney, B. (2011). A model of caregiving through the end of life. *Western Journal of Nursing Research*, *34*, 174-193.

Peters, S. (2020). *Aging with agency: Building resilience, confronting challenges, and navigating eldercare*. New York, NY: North Atlantic.

Plöthner, M., Schmidt, K., De Jong, L., Zeidler, J., & Damm, K. (2019). Needs and preferences of informal caregivers regarding outpatient care for the elderly: A systematic literature review. *BMC Geriatrics*, *19*(1), 82.

Podsiadlowski, A., & Fox, S. (2011). Collectivist value orientations among four ethnic groups: Collectivism in the New Zealand context. *New Zealand Journal of Psychology*, *40*, 5-18.

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, *8*, 5-23.

Prunty, M. M., & Foli, K. J. (2019). Guilt experienced by caregivers to individuals with dementia: A concept analysis. *International Journal of Older People Nursing*, *14*(2), 1-13.

Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health*, *13*, 143-154.

Quinn, C., Nelis, S. M., Martyr, A., Morris, R. G., Victor, C., & Clare, L. (2020). Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. *Aging & Mental Health*, *24*, 1505-1513.

Rayment, G., Swainston, K., & Wilson, G. (2018). Using photo-elicitation to explore the lived experience of informal caregivers of individuals living with dementia. *British Journal of Health Psychology*, *24*, 102-122.

Reed, C., Belger, M., Dell'Agnello, G., Wimo, A., Argimon, J. M., Bruno, G., … Vellas, B. (2014). Caregiver burden in Alzheimer's disease: Differential associations in adult-child and spousal caregivers in the GERAS observational study. *Dementia and Geriatric Cognitive Disorders Extra*, *4*(1), 51-64.

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Reports*, *15*(7), 367.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.

Robinson, A., Lea, E., Hemmings, L., Vosper, G., McCann, D., Weeding, F., & Rumble, R. (2011). Seeking respite: Issues around the use of day respite care for the carers of people with dementia. *Ageing and Society*, *32*, 196-218.

Rose, K. M., & Lopez, R. P. (2012). Transitions in Dementia Care: Theoretical Support for Nursing Roles. *The Online Journal of Issues in Nursing*, *17*(2), 4.

Rosenzweig, A. S. (2012). *The harsh realities of Alzheimer's care: An insider's view of how people with dementia are treated in institutions*. Santa Barbara, CA: Praeger.

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, *55*, 309-319.

Rowles, G. D., Oswald, F., & Hunter, E. G. (2003). Interior living environments in old age. In H. Wahl, R. Scheidt, & P. Windley (Eds.), *Annual review of gerontology and geriatrics* (pp. 167-194). New York, NY: Springer.

Rozanova, J., Miller, E. A., & Wetle, T. (2014). Depictions of nursing home residents in US newspapers: Successful ageing versus frailty. *Ageing and Society*, *36*, 17-41.

Russell, E., & Nightingale, M. (2019, March 13). Rotten care: Elderly rest home residents dying due to low level of help – union. *NZ Herald* [Auckland].

Ryan, A. A., & Scullion, H. F. (2000). Nursing home placement: An exploration of the experiences of family carers. *Journal of Advanced Nursing*, *32*, 1187-1195.

Saldaña, J. (2003). *Longitudinal qualitative research: Analyzing change through time*. New York, NY: Rowman Altamira.

Scott, K., Webb, M., & Kostelnick, C. (2018). *Long-term caring: Residential, home and community aged care* (4th ed.). New York, NY: Elsevier.

Searing, D. D. (1995). The psychology of political authority: A causal mechanism of political learning through persuasion and manipulation. *Political Psychology*, *16*, 677-696.

Seidel, D., & Thyrian, J. R. (2019). Burden of caring for people with dementia – comparing family caregivers and professional caregivers. A descriptive study. *Journal of Multidisciplinary Healthcare*, *12*, 655-663.

Shaji, K., George, R., Prince, M., & Jacob, K. (2009). Behavioral symptoms and caregiver burden in dementia. *Indian Journal of Psychiatry*, *51*, 45-49.

Shepherd, H., Livingston, G., Chan, J., & Sommerlad, A. (2019). Hospitalisation rates and predictors in people with dementia: A systematic review and meta-analysis. *Alzheimer's & Dementia*, *15*, 489-490.

Silver, J. (2013). Narrative psychology. In C. Willig (Ed.), *Introducing qualitative research in psychology* (pp. 143-155). Berkshire: Open University Press.

Skirbekk, H., Middelthon, A., Hjortdahl, P., & Finset, A. (2011). Mandates of trust in the doctor–patient relationship. *Qualitative Health Research*, *21*, 1182-1190.

Soong, A., Au, S. T., Kyaw, B. M., Theng, Y. L., & Tudor-Car, L. (2020). Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: A scoping review. *BMC Geriatrics*, *20*(1) 1-17.

Spillman, B. C., & Long, S. K. (2009). Does high caregiver stress predict nursing home entry? *Inquiry Journal*, *46*, 140-161.

Stephens, C. (2011). Narrative analysis in health psychology research: Personal, dialogical and social stories of health. *Health Psychology Review*, *5*, 62-78.

Stephens, C., & Breheny, M. (2013). Narrative analysis in psychological research: An integrated approach to interpreting stories. *Qualitative Research in Psychology*, *10*, 14-27.

Sury, L., Burns, K., & Brodaty, H. (2013). Moving in: Adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, *25*, 867-876.

Synergia. (2019). *Respite in New Zealand: We must do better*. Retrieved from http://carers.net.nz/wp-content/uploads/2019/05/We-Must-Do-Better-Respite-Report-FINAL-March-2019.pdf

Teng, C., Loy, C., Sellars, M., Pond, D., Latt, M., Waite, L. M., … Tong, A. (2020). Making decisions about long-term institutional care placement among people with dementia and their caregivers: Systematic review of qualitative studies. *Gerontologist*, *60*, 326-329.

Thorson, J. (2013). *Aging in a changing society*. New York, NY: Routledge.

Timmons, S., O'Shea, E., O'Neill, D., Gallagher, P., De Siún, A., McArdle, D., … Kennelly, S. (2016). Acute hospital dementia care: Results from a national audit. *BMC Geriatrics*, *16*(1) 1-10.

Townsend, M. D. (2011). *Māori and Dementia: Māori health professionals' perceptions of dementia, support offered and suggested improvements* (Master's thesis, University of Waikato, Hamilton, New Zealand).

Tretteteig, S., Vatne, S., & Rokstad, A. M. (2017). Meaning in family caregiving for people with dementia: A narrative study about relationships, values, and motivation, and how day care influences these factors. *Journal of Multidisciplinary Healthcare*, *10*, 445-455.

Umeogu, B., & Ifeoma, O. (2012). Constructionist theory of representation in language and communication: A philosophical analysis. *Open Journal of Philosophy*, *2*, 130-135.

Unger, J. B. (2011). Cultural identity and public health. In S. J. Schwartz, K. Luyckx, & V. L. Vignoles (Eds.), *Handbook of identity theory and research* (pp. 811-825). New York, NY: Springer Science & Business Media.

United Nations. (2019). *World population prospects 2019*. Retrieved from https://population.un.org/wpp/Publications/Files/WPP2019_Highlights.pdf

United Nations. (2020) *World population ageing 2020 highlights.* Retrieved from https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/files/documents/2020/Sep/un_pop_2020_pf_ageing_10_key_messages.pdf

Van Steenwinkel, I., Baumers, S., & Heylighen, A. (2012). Home in later life. *Home Cultures*, *9*, 195-217.

Van Wijngaarden, E., Van der Wedden, H., Henning, Z., Komen, R., & The, A. (2018). Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PLOS ONE*, *13*(6), 1-21.

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *International Journal of Geriatric Psychiatry*, *31*, 1277-1288.

Vincent, K. A. (2013). The advantages of repeat interviews in a study with pregnant schoolgirls and schoolgirl mothers: Piecing together the jigsaw. *International Journal of Research & Method in Education*, *36*, 341-354.

Wallerstein, J. (2019). *The good marriage: How and why love lasts*. Lexington, MA: Plunkett Lake.

Warburton, J., & Savy, P. (2012). The aged care sector: Residential and community care. In E. Willis, L. Reynolds, & H. Keleher (Eds.), *Understanding the Australian health care system* (pp. 121-138). Chatswood, Australia: Elsevier.

Weir, K. (2012). Revising your story. *PsycEXTRA Dataset*, *43*, 28.

Williams, C. C. (2008). Re-thinking the future of work: Beyond binary hierarchies. *Futures*, *40*, 653-663.

Wilson, D. M., Vihos, J., Hewitt, J. A., Barnes, N., Peterson, K., & Magnus, R. (2013). Examining waiting placement in hospital: Utilization and the lived experience. *Global Journal of Health Science*, *6*(2), 12-22.

Wilson, P. D. (2015). *The caregiving trap: Solutions for life's unexpected changes*. New York, NY: Morgan James.

Wong, G., & Breheny, M. (2018). Narrative analysis in health psychology: A guide for analysis. *Health Psychology and Behavioral Medicine*, *6*, 245-261.

Work and Income. (n.d.). Residential care subsidy. Retrieved October 5, 2020, from https://www.workandincome.govt.nz/products/a-z-benefits/residential-care-subsidy.html

Zarit, S. H., & Talley, R. C. (Eds.). (2013). *Caregiving for Alzheimer's disease and related disorders: Research, practice, and policy*. New York, NY: Springer.

Zegwaard, M. I., Aartsen, M. J., Grypdonck, M. H., & Cuijpers, P. (2017). Trust: An essential condition in the application of a caregiver support intervention in nursing practice. *BMC Psychiatry*, *17*(1), 1-10.

Appendix A – Original Study Ethics Approval

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
Freyberg Building
20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

02 August 2016

Dr Rosemary Gibson
Sleep/Wake Research Centre
Massey University
Wellington Private Bag 756

Dear Dr Gibson

Re:	**Ethics ref:**	**16/CEN/101**
	Study title:	Factors Affecting the Sleep of Family Carers: A Survey of those Supporting People with a Cognitive Impairment or Dementia in their own Home

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.
In future, please ensure that all submitted documents are final versions and not drafts. The submitted poster is a draft version.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your **next progress report** is due by **01 August 2017**.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix B – Original Study Invitation

'SLEEP~WAKE' research centre
'MOE TIKA~MOE PAI'

Massey University

Sleep and Health of Family Carers: Follow-up Interviews

Lead investigator: Dr Rosie Gibson
18th June 2018

Hello,

Thank you for taking part in the 2016-17 survey study concerning sleep of people caring for a family member with a cognitive impairment or dementia. This original survey is now being analysed and reports will be made available soon. Currently I am looking for volunteers to take part in follow-up interviews as we would like to gain a better understanding of the sleep experience with caregiving and transitions into formal care.

I am writing to offer you an interview as you signed on to our mailing list regarding future research studies. This information sheet is to help you decide if you'd like to take part. It sets out why I am doing this follow-up study, what is involved, and what the benefits and risks might be. Please take a few moments to read this. You may want to talk about the study with other people, such as family, whānau, friends, or your local Alzheimers or Dementia association. Feel free to do this. You can also contact me (Rosie Gibson) on Freephone 0800 MY SLEEP (69 75337), direct dial: 04 9793258, or email r.gibson@massey.ac.nz if you have any questions. Whether or not decide to take part is your choice. It will not affect the support you receive.

Why are we doing follow-up interviews?

Previous research, including the postal survey you took part in, indicates that sleep problems are a common and challenging aspect of cognitive impairment and dementia. Sleep problems can contribute to waking symptoms, thus affecting the health and wellbeing of the those with dementia as well as family carers. Previous research also shows that sleep problems may contribute to decisions around moving family members with a cognitive impairment or dementia into formal care (e.g. residential or hospitalised care). However, the experiences and voices of families affected are missing from this research.

I am interested in talking to approximately 20 family carers who have recently transitioned their family member with a cognitive impairment or dementia into formal care. The aim of these interviews are to understand how sleep changes with the course of dementia and the role of sleep problems in decisions around formal care.

Who can take part?

To be eligible to take part you need to:

- Have been a carer/support person for a family member with a cognitive impairment or dementia who previously lived with you.
- Have transitioned that person into formal care setting (e.g. residential or hospitalised care) since taking part in the original postal survey.
- Not currently have a clinical sleep disorder or mental health condition (e.g. sleep apnoea, depression or dementia).

Note, you can still take part if:

- Your family member has passed away since the transition to formal care.
- You consider yourself a good sleeper.

Please contact me if you are unsure if you are eligible.

What would your participation involve?

To take part in this study you firstly need to complete a short questionnaire concerning who you are, your health and sleep. This can be completed by post or over the phone, your choice. You will also need to check off and sign a consent form before your interview. It is expected that interviews will last approximately 1 hour and will take place between June-August 2018. Interviews can be conducted face-to-face (e.g. in your home or at a public meeting room) or via telephone or videoconference. Location will depend on your preference and the logistics of geographical region and timing (you can discuss this with me to find a convenient option).

The interview

Your Interview will be loosely constructed, allowing for you to provide as little or much detail as you feel comfortable. During the interview I would like to explore the following topics:

- The experience of providing informal care for a family member with cognitive impairment or dementia
- How sleep changed for you both as the disease progressed
- How sleep problems were (or were not) managed
- The role of sleep disturbances in the decision to transition your family member into formal care
- How you are sleeping post the transition to care

The interview will be audio recorded and transcribed, you will be sent your transcript and will have some time to edit it should you wish. Your transcript will be analysed with the other participants' with the aim of understanding sleep changes with family caring.

What are the possible benefits and risks in participating?

Taking part in this follow-up interview is voluntary. If you decide to particulate, you will be contributing to a better understanding of the sleep of family carers and people with cognitive impairment or dementia. The information that you provide will be valuable in guiding research, policy and services to improve community health and wellbeing.

You may find some of the topics of a personal or sensitive nature (e.g. discussing the impact of your family member's sleep-related behaviours). By taking part you are not obliged to answer all of the questions if you do not feel comfortable. You are welcome to have a family member, or another person present for support.

If you have any questions or concerns regarding the survey, you can contact the me or other using the details below. To thank you for your time, we will provide you with a $20 grocery voucher.

What will happen with your information?

As with the original survey data, all of your information will be kept strictly confidential. Paper copies of the screening questionnaires and consent forms will be kept in a secure cabinet at the Sleep/Wake Research Centre, Massey University. Interviews will be transcribed using a private transcription service (with a confidentiality agreement). Electronic data will be accessible by password by the immediate research team only.

I expect around 20 people to take part. Analysis and reports will describe grouped themes, these may be illustrated using quotes from your interview. However no information which could identify you or your family will be used.

A summary of the findings will be available to you in 2019. This will be via a report mailed directly to you as well as via Alzheimers New Zealand and Dementia Organisations. Findings will also be reported on the Sleep/Wake Research Centre's website and presented at local and/or international conferences as well as published in a scientific journal.

What do I do now?

Please take the time to consider this opportunity and discuss with your family, friend or healthcare provider if you wish. If you are interested in participating, please contact me to ask any questions, begin the consent process, and set a convenient time for your interview.

Thank you for taking the time to consider being involved in this research.

This follow-up study has been approved by the Central Health and Disability Ethics Committee (ref: 16/CEN/101/AM01). It is being funded by grants from the Lotteries Health Commission. If you have any questions, concerns or complaints about the study at any stage, you can contact the team at the Sleep/Wake Research Centre:

Lead Investigator - Rosie Gibson, PhD
Freephone: 0800 MY SLEEP (69 75337)
Phone: 04 9793258
Email: r.gibson@massey.ac.nz
Administrator – Travis Steenekamp
Phone: 04 979 3055
Email: swrc@massey.ac.nz
Director, Sleep/ Wake Research Centre - Philippa Gander, PhD
Phone: 04 3800633
Email: p.h.gander@massey.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Appendix C – Original Study Consent Form

CONSENT FORM
Sleep and Health of Family Carers: Follow-Up Interviews

Please tick to indicate you consent to the following:

I have read and I understand the information sheet dated 5.3.2018 for volunteers taking part in a follow-up interview concerning sleep changes for family carers and decisions around formal care.	Yes ☐	No ☐
I understand that I have been contacted about these interviews as I took part in the original survey component of the research and signed onto a mailing list concerning future research.	Yes ☐	No ☐
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	No ☐
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	No ☐
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	No ☐
I understand that taking part in this interview component is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my care or support	Yes ☐	No ☐
I consent to the research staff collecting and processing my information, including information about my health.	Yes ☐	No ☐
I consent to my interview being audio-recorded and that recording being transcribed for analysis.	Yes ☐	No ☐
I understand that I will be sent a copy of my transcript for review.	Yes ☐	No ☐
I understand that I can withdraw from the study at any time and this will in no way affect my support.	Yes ☐	No ☐
Direct quotes may be used, but no material which could identify me or my family members will be used in any reports on this study.	Yes ☐	No ☐
I understand that my participation in this study is confidential. Direct quotes may be used, but no material which could identify me or my family members will be used in any reports on this study.	Yes ☐	No ☐
I know who to contact if I have any questions about the study in general.	Yes ☐	No ☐
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

Please indicate if you would prefer to have your interview conducted…..

face to face ☐

by telephone/videoconference ☐

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: Date:

Researcher contact:
Dr. Rosie Gibson
Postdoctoral Fellow Sleep/Wake Research Centre
College of Health, Massey University, Wellington, PO Box 756, New Zealand
Telephone: 04 9793258
r.gibson@massey.ac.nz

Appendix D – Interview Schedule

Carers follow up interviews

Prior – background to me
How long as X been in residential care and where are they?

Aims of the interview

- To document your sleep journey as someone who has been a family carer and been through the process of transition to formal care
- To represent the stories of yourself and others as this could not be captured in the survey's alone
- Better understand the role of sleep health in caregiving situations and decisions around formal care

Schedule

- The experience of providing informal care for a family member with cognitive impairment or dementia
  - Could you tell me a little bit about yourselves and what it was like supporting X here at home?
  - Thinking back, how were you sleeping before you were faced with dementia?
  - Had sleep changed for you much over life so far?
- How sleep changed for you both as the disease progressed
  - Could you tell me the story of how your sleep changed as X's condition progressed through to moving them into formal care?
  - Thinking back what do you think were the causes of any sleep problems, did these causes change with the progression of dementia
- How sleep problems were (or were not) managed
  - How did you cope with sleep problems of X – and what about you, how did you cope in times of sleep loss?
  - Did you have any strategies or behaviours to manage?
  - Use respite at all?
- The role of sleep disturbances in the decision to transition your family member into formal care
  - Clearly moving a loved one into formal care can be a difficult decision, what was this process like for you?
  - Thinking back to making the decision to move X into X, how much of a role would you say problem sleep was in your consideration and final decisions ?
- How you are sleeping post the transition to care
  - What is your sleep like now?
  - Have there been any events or turning points since the transition which have influenced your sleep health?
- Is there anything we have missed?
  - Have we come full circle, back to the present?
  - Is there anything else you'd like to share before I turn the recorder off?

Appendix E –Original Study Follow Up Newsletter and Faye Wright's Introduction

'SLEEP~WAKE' research centre
'MOE TIKA~MOE PAI'

Massey University

Sleep and Health of Family Carers: Follow-up Interviews

Lead investigator: Dr Rosie Gibson
21st May 2019

News and Call for Feedback

Dear

Many thanks again for taking part in my research interviews concerning sleep whilst caring for someone with dementia. It has been an honour to represent this aspect of carers' wellbeing. I am confident that the findings will be beneficial for future carers as well as informative for community supporters, clinicians and researchers.

It has been several months since the interviews, so I wanted to share my progress on this project, invite your feedback, and introduce Faye Wright, an upcoming Psychology student who will collaborate on the project for her Master's thesis from July.

In this newsletter I will cover:

1. Handling of the interview data
2. Who you are as a group
3. Some of the key themes concerning sleep across the course of caring
4. Intentions for writing up and sharing findings
5. Moving forward - Faye's thesis concerning the experiences of family carers

1. Handling of the interview data

The interviews covered experiences supporting someone with dementia at home. They particularly examined how sleep was affected throughout the progression of dementia and post transition into residential care. The interviews were transcribed using a professional and confidential service. Your name, the names of your family members, and key place names and care providers were changed to make the transcripts anonymous. The transcripts were checked against the original interview recordings by my wonderful research assistant Amy Helm. Amy and I examined the transcripts to see how sleep changed across the trajectory of dementia-related care. We coded the transcripts, wrote case studies, and selected examples stories and quotes to illustrate them. We have been doing this under the guidance of Professor Philippa Gander, an expert in sleep across the lifespan and Associate Professor Mary Breheny, an expert in analysing interview data with a keen interest in ageing and caregiving.

2. Who you are as a group

Twenty people participated in this interview study. All participants had transitioned the person they were supporting into formal care within two years of the original sleep survey. For some of you, that person had since passed way. The interviews were conducted face to face for most people living in the lower North Island and over the telephone for those living in more distant, rural locations. The majority of people in this study had been supporting a partner/spouse with dementia (17). Some of you had been supporting a parent, grandparent or friend. The types of symptoms experienced varied due to differing dementia-related diagnoses.

3. Key themes concerning sleep across the course of caring

From our analyses, we whittled down the content within the many stories shared to identify some common themes regarding sleep. These are summarised below and in the table enclosed. The themes can be grouped over time by considering how sleep changing during care. For example, people talked about sleep before caring, whilst caring, around time of transition to residential care, and then following this transition. Some people also talked about sleep following the death of the person they cared for.

Call for feedback

Please contact me by the 30th June 2019 if you feel:

- there is something important missing or misrepresented in the summaries that we can discuss and amend if necessary
- You would like to receive a copy of your full transcript
- You would like to change the pseudonym I used for yourself or the person you supported (these were picked at random and will be used to protect your identity in writing up the findings and any quotations)
  Yours are:

My contacts: Rosie, email: r.gibson@massey.ac.nz, phone: 04 9793258

Please note: not all of the themes may be applicable to you. The use of "you" here refers more globally to the group rather than necessary *you* in particular.

Sleep pre carer role

Most of you set the scene by discussing your experiences with sleep before caring. This appears to influence how we manage periods of sleep disturbance. Sleep identity was on a continuum from "Always been a good sleeper" to "Never slept well anyway". Some of you fit in-between, e.g. had experienced overcome periods of poor sleep, managed on little sleep, shift working etc.

Sleep during carer role

During the busy time caring for someone with dementia, many of you described sleep disruptions related to the high responsibilities of care, i.e. physically and mentally supporting the care recipient in the night. These are described as "Being responsible 24/7" and/or being "On high alert day and night". Care requirements overnight varied but common responsibilities included toileting or continence-related support, guiding back to bed, and comforting while unable to sleep or after nightmares/hallucinations. Many of you reported symptoms of insomnia. The ability to successfully get to sleep and stay asleep was limited due to the "timing of sleep being dictated by that of the care recipient". Some of you reported "being unsure of sleep", and expecting to be woken or needed in the night. Feelings of stress or grief were also common and affected the ability to sleep easily or well.

A common story regarding the impact of sleep disruptions was that it got "progressively worse". This theme encompasses the gradual deterioration of carers sleep as dementia progressed. The impact of sleep disturbances was described to "creep up". Some of you reported retrospectively that you were unaware of the impact of changes to your sleep until

after the person you supported moved away. Others were aware but described the limited options for facilitating you own sleep or wellbeing ("I was tired but I had no choice"). Many described functioning on "autopilot" or "high alert" with a strong will to prioritise and maintain the wellbeing of your family member at home for as long as possible.

Regarding management of sleep problems, many of you described strategies you had tried to improve the sleep of yourself or the person you were supporting. The theme "I tried lots of things" encompasses how resourceful and pragmatic many of you were. These included practical solutions to monitor and ensure safety of your family member in the night. For others, careful scheduling of sleep was important. Even when in-home care was available, support to sleep well was seldom mentioned and the timing of assistance was not usually appropriate for sleep. Respite also posed a challenge and unfortunately the time was often limited with regards to sleep recovery. Furthermore, sleep disturbances were often described as exacerbated after respite care due to high responsibilities and readjusting.

For all of you there was a point in the interview where we talked about making decisions around transitioning your family member to residentia care or hospital. Events and reasons for the transition were varied between you (e.g. from realising additional support was required, to a more direct medical event which led to hospitalisation and reassessment). The stories here are very rich and outside of the original research question regarding sleep. Fortunately, Faye Write has come to us interested in understanding this period in the cares journey. See below (point 5) and Faye's letter attached for more info.

Sleep around transition

Around the period of transition, many of you described sleep being affected by a period of "crashing" either through a state of relief and catching up on sleep ("sleeping like a log"), or more of a debilitating effect of sleep deprivation taking over e.g. "I couldn't put one foot in front of the other". For others "The busy momentum continued" and sleep remained disrupted.

As noted above, many of you reflected that you were more sleep deprived than you thought. It wasn't until after your family member had moved out that you realised how much of an impact the caregiving role had made on your sleep and waking function. Considering this, many of you suggested that sleep should be prioritised for carers, acknowledging the impact that sleep deprivation likely had on your health, mood, and/or wellbeing, thereby also affecting the ability to manage the overall caregiving situation.

Grief was common around the transition to residential care. This affected the ability to get to sleep and stay asleep for some people. Missing them, having concerns regarding their wellbeing, and getting used to no longer needing to sleep on such high alert was important at that time.

Sleep post transition

Many of you described the situation post transition like "being in limbo" and a period where still the "responsibilities don't end". This was associated to feelings of grief as well as concern for the person with dementia. Alternatively (or additionally) sleep was affected due to the lasting impact of the disrupted schedules and habits created through the

caregiving situation. This made it challenging to fall asleep and stay asleep despite no longer being woken by someone else.
Many people did report enjoying "sleeping on my time". The luxury of being able to reclaim a sense of control and identity around sleeping as well as waking life was expressed with regards to timing and routines. This included being able to comfortably lie awake at night if need be and the freedom to nap in the day. At this stage, many of you expressed an insight into the importance of maintaining sleep with regards to your own health, wellbeing, and safety . You expressed an awareness of the factors which could affect your sleep and what works with regards to managing sleep disturbances for yourself as well as others.

With the increased opportunity to sleep a lot of you reported an influx of dreaming (" I'm dreaming, dreaming, dreaming!"). Unfortunately, many of you described the content of the dreams as unpleasant. Nightmares associated with the person with dementia, family relationships, and health were common. This is not unusual considering the common themes around grieving as well as a sudden rebound of sleep. Many expected that as the transitional period settled down, so would the sleep and intense dreaming. Some were fortunate to have a rebound of dreams of a more pleasant nature. This added to themes around the luxury of reclaiming sleep status post transition.

Sleep post death

For eight of you, your family member with dementia had died since taking part in the original survey and transitioning to care. As with your accounts regarding transitions to care, the events around death were diverse, rich and personal. Regarding sleep around this time, the state of bereavement was reported by many of you to affect your ability to get to sleep and stay asleep ("I miss them dreadfully"). However, this was typically presented as normal and a natural part of the experience of widowhood, which would likely resolve in time. Another common theme for this time was concerning that of a sense of closure or relief. Sleep was slowly improving with the adaptation to the nights and days without the high physical and mental responsibilities of caregiving described in the earlier themes, and a period of rebuilding the self and lifestyle was beginning.

Summary

When actively involved in supporting a family member with dementia, carers sleep often becomes progressively disrupted. This is due to the unpredictable nature of dementia-symptoms, routines and the 24/7 responsibilities, which can cause a state of being highly alert despite sleep deprivation. Many attempted to facilitate better sleep and wellbeing for those with dementia, often sacrificing their own self-care. Retrospectively, carers reported being exhausted. At the time of transition, carers either report a period of crashing, or the continuation of being or feeling busy. Grief was common throughout. Post-transition, sleep disruptions were associated with insomnia, poor sleep habits, or nightmares. Many were optimistic that sleep would improve with the grieving process and were enjoying the luxury of managing their own sleep timing and activities. The key themes across time are presented in the table enclosed.

caregiving situation. This made it challenging to fall asleep and stay asleep despite no longer being woken by someone else.
Many people did report enjoying "sleeping on my time". The luxury of being able to reclaim a sense of control and identity around sleeping as well as waking life was expressed with regards to timing and routines. This included being able to comfortably lie awake at night if need be and the freedom to nap in the day. At this stage, many of you expressed an insight into the importance of maintaining sleep with regards to your own health, wellbeing, and safety . You expressed an awareness of the factors which could affect your sleep and what works with regards to managing sleep disturbances for yourself as well as others.

With the increased opportunity to sleep a lot of you reported an influx of dreaming (" I'm dreaming, dreaming, dreaming!"). Unfortunately, many of you described the content of the dreams as unpleasant. Nightmares associated with the person with dementia, family relationships, and health were common. This is not unusual considering the common themes around grieving as well as a sudden rebound of sleep. Many expected that as the transitional period settled down, so would the sleep and intense dreaming. Some were fortunate to have a rebound of dreams of a more pleasant nature. This added to themes around the luxury of reclaiming sleep status post transition.

Sleep post death

For eight of you, your family member with dementia had died since taking part in the original survey and transitioning to care. As with your accounts regarding transitions to care, the events around death were diverse, rich and personal. Regarding sleep around this time, the state of bereavement was reported by many of you to affect your ability to get to sleep and stay asleep ("I miss them dreadfully"). However, this was typically presented as normal and a natural part of the experience of widowhood, which would likely resolve in time. Another common theme for this time was concerning that of a sense of closure or relief. Sleep was slowly improving with the adaptation to the nights and days without the high physical and mental responsibilities of caregiving described in the earlier themes, and a period of rebuilding the self and lifestyle was beginning.

Summary

When actively involved in supporting a family member with dementia, carers sleep often becomes progressively disrupted. This is due to the unpredictable nature of dementia-symptoms, routines and the 24/7 responsibilities, which can cause a state of being highly alert despite sleep deprivation. Many attempted to facilitate better sleep and wellbeing for those with dementia, often sacrificing their own self-care. Retrospectively, carers reported being exhausted. At the time of transition, carers either report a period of crashing, or the continuation of being or feeling busy. Grief was common throughout. Post-transition, sleep disruptions were associated with insomnia, poor sleep habits, or nightmares. Many were optimistic that sleep would improve with the grieving process and were enjoying the luxury of managing their own sleep timing and activities. The key themes across time are presented in the table enclosed.

This study was approved by the Central Health and Disability Ethics Committee (ref: 16/CEN/101/AM01). It is being funded by grants from the Lotteries Health Commission and the Health Research Council. If you have any questions, concerns or complaints about the study at any stage, you can contact me on Phone: 049793258, Email : r.gibon@massey.ac.nz. You can also contact the Director of the Sleep/Wake Research, Philippa Gander on: Phone: 04 3800633, Email: p.h.gander@massey.ac.nz.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on: Phone: 0800 555 050, Email: advocacy@hdc.org.nz. You can also contact the health and disability ethics committee (HDEC) that approved this study on:
Phone: 0800 4 ETHICS, Email:hdecs@moh.govt.nz

Table illustrating key sleep-related themes by time point

	Pre carer role		
Sleep identity	Continuum: Always been good sleeper ---------- Never slept well anyway		
	During care role	**Around transition**	**Post transition**
How sleep affected	Being responsible 24/7 On high alert day and night	The busy momentum continued	Responsibilities don't end
	Timing dictated by care recipient	I just crashed	Sleeping on my time/definitely better
	Unable to be sure of sleep		
Impact of sleep disturbances	Sleep got progressively worse	Should have prioritised sleep	Sleep affects my health
	I was tired but I had no choice	Didn't realise how tired I was	
Managing sleep disturbances	I tried lots of things	Some teary nights	I'm dreaming, dreaming, dreaming!
	Realisation of need	I couldn't have managed	**Post death (n=8)**
			I miss them dreadfully
			A state of closure

Hello Research Participants

I am completing a Master of Arts in Psychology with Massey University. As one of the requirements I must complete a research thesis. I have been offered the opportunity to analyse the interview data which you and others provided as a follow-up to the research survey: Sleep and Health of Family Carers.

I plan to use narrative analysis to analyse the information you supplied. The focus of my project will be to understand the transitional process that caregivers experience when moving their family member or friend into residential care.

I wanted to introduce myself as part of letting you know that I will value your data and treat it in a respectful way. I have been married for twenty-six years and have two adult children. My mother lived with dementia at the end of her life. I have also worked as a counsellor. For a year, I counselled caregivers of people living with dementia through Alzheimers Tauranga. I have a strong personal and professional interest in dementia and a commitment to understanding the story that caregivers provide surrounding their journey with the people they care for.

I hope the outcome of my research will be provide new insights regarding caregivers' experiences of care and transitions from home to residential care.

Yours Sincerely

Faye Wright
1st May 2019